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DECISION MAKING IN CLINICAL ONCOLOGY

An ethical exploration of cancer treatment refusal

The study presented in this thesis was performed at the Center of Ethics and Philosophy, department of Philosophy and Medical Ethics, VU University Medical Center, Amsterdam, The Netherlands. The department of Philosophy and Medical Ethics participates in the Netherlands Graduate Research School of Science, Technology and Modern Culture (WTMC), which has been accredited by the Royal Netherlands Academy of Arts and Sciences (KNAW).

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VRIJE UNIVERSITEIT

DECISION MAKING IN CLINICAL ONCOLOGY

An ethical exploration of cancer treatment refusal

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof.dr. T. Sminia,
in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de faculteit der Geneeskunde
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De Boelelaan 1105

door

Titia van Kleffens

geboren te Westmaas

promotor: prof.dr. E. van Leeuwen

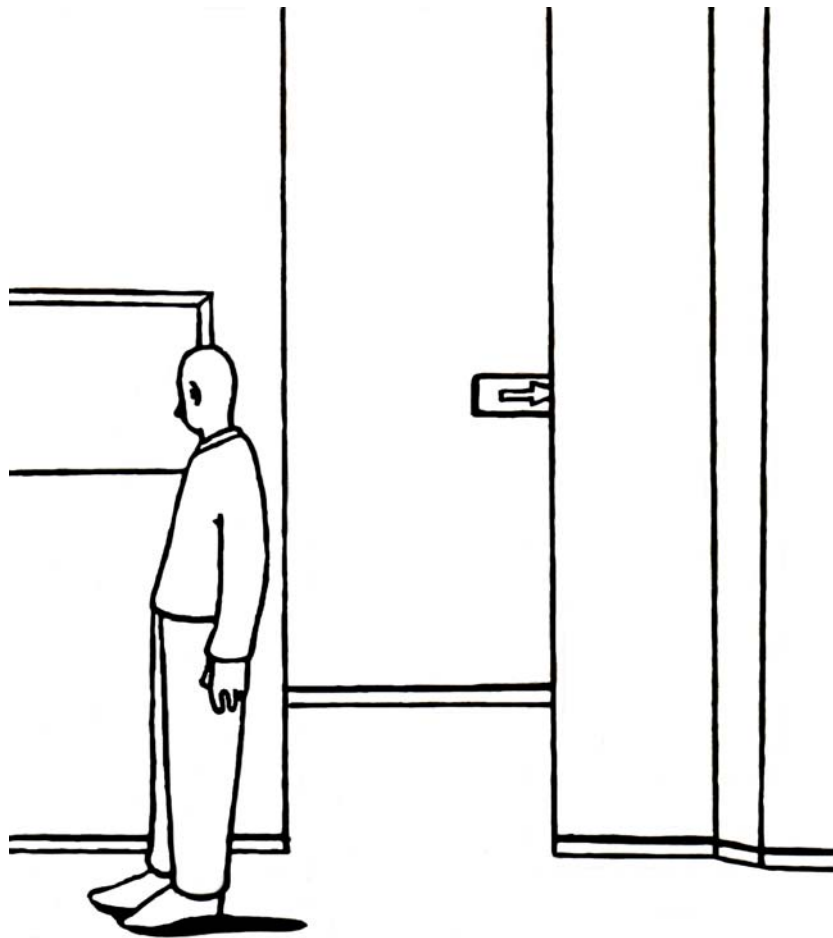
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For reasons of consistency within this thesis, spelling, layout, and some terms have been standardized throughout the text. As a consequence, the chapters may differ from the articles that have been published.

Introduction



Introduction

Every year more than 69.000 people in the Netherlands are diagnosed with cancer.¹ With 27% of deaths every year, cancer is the second main cause of death, following heart and blood vessel failures.² The most common treatment for cancer patients is surgery, radiation therapy, or systemic therapy (e.g., chemotherapy, hormonal therapy, and immunotherapy). Treating cancer patients can have two intentions: a curative or a palliative intention. Although prognostic outcomes for cancer patients have become better, still approximately 50% of cancer patients cannot be cured and are treated with palliative intention.³

Decision making about adequate cancer treatment has long been an asymmetrical process: the physician used his or her skills and knowledge to choose the best optional treatments for his or her patient. In today's health care, patients are more and more stimulated to play an active role in the decision-making process and are even expected to be involved in decisions about their medical care.⁴ During the last two decades, patients have tended to move toward a more active role in making decisions about their medical treatment.⁵⁻⁸ In clinical oncology, most of the time, the physician provides the patient with medical information, he or she explains the options, and gives a treatment recommendation. The majority of all cancer patients accepts those recommended treatments. In some cases, however, a patient's decision-making process ends up in refusing treatment. Refusal then means that the patient does not want to start treatment at all, wants to stop during treatment, or refuses a part of a recommended treatment but accepts another part (e.g., a woman with breast cancer who has been recommended to have surgery and in addition chemotherapy, wants to undergo surgery, but refuses chemotherapy).

Treatment refusal and its moral applications have often been discussed concerning issues such as Do Not Resuscitate (DNR) orders,⁹ withdrawal of life-sustaining treatment (for example, ventilation),¹⁰ blood transfusions for Jehovah's Witnesses,^{11,12} and coercion in psychiatry.¹³⁻¹⁵ These discussions are often made from the perspective of patient autonomy as conflicting with the responsibilities of clinicians. Patient autonomy is also the central value cited in defence of honouring refusals based on religious values.^{11,12} In psychiatry, patient autonomy is also

much emphasized to refer to conflicts between patients having a right to refuse treatment (as long as the patient does not harm others) and physicians being paternalistic in coercing patients.¹³⁻¹⁵ Treatment refusal in clinical oncology has not yet received much attention. In this thesis, an ethical exploration is given of patients' and physicians' considerations concerning treatment refusal in clinical oncology.

Objectives and research question

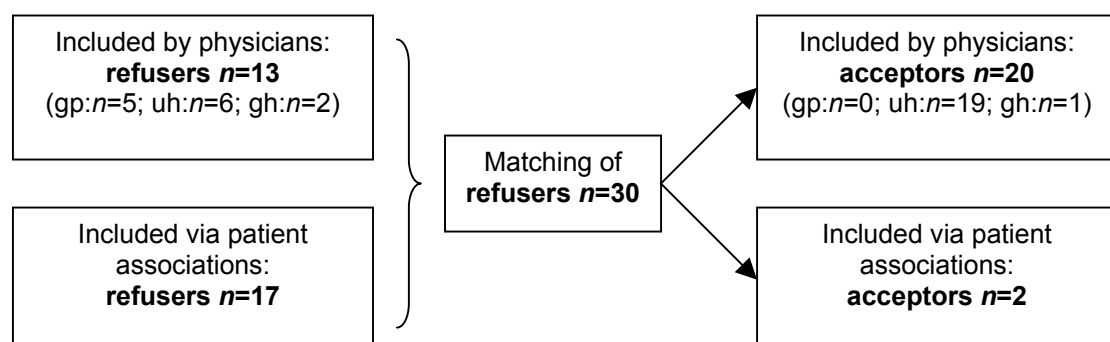
This thesis gives an ethical exploration of treatment refusal in clinical oncology. The objectives of the study are twofold: firstly, to provide insight into patients' and physicians' considerations concerning treatment refusal in clinical oncology. Secondly, to clarify the concept of patient autonomy in the context of cancer treatment refusal. The main research question of the study is: how does the concept of patient autonomy take shape in the decision-making process on oncological treatment, particularly in cases of treatment refusal? The focus is among others on (1) the motives of patients to refuse recommended oncological treatment, (2) physicians' attitudes to treatment refusal, and (3) the position of the patient and the role of the physician in the decision-making process, with a special focus on issues of patient autonomy.

Methodology

The considerations of patients and physicians in the decision-making process on oncological treatment have been explored using qualitative research methods. The study is mainly based on interviews with physicians and with patients who refused oncological treatment. In order to compare between patients who refused and who accepted recommended treatment, interviews were carried out with patients who accepted oncological treatment as well. At the start of the study, observational studies were performed in order to be introduced in the field of research, to make a first inventory of physician and patient considerations and deliberations regarding treatment decision making, and to formulate interview topics.

For the interview study, physicians from different disciplines and settings were approached to include patients: (general) oncologists, surgeons, radiotherapists, haematologists, gynaecologists, urologists, lung specialists, and general practitioners. Physicians approached 47 patients. Thirty-three of these patients were included in the study (Figure 1). The response rate of the patients recruited by physicians was 70%. This response rate needs to be interpreted with certain caution because it is not clear how many potential participants were asked to participate. Only the informed consent forms of those patients who actually wanted to participate in the study were received. Patients were asked to participate by general practitioners ($n_{pat}=5$), and by specialists in a university hospital ($n_{pat}=25$) and in five general hospitals ($n_{pat}=3$) in the Netherlands. The hospitals were located in Alkmaar, Amsterdam, Hilversum, Hoorn, Purmerend, and Zaandam. The general practitioners had their practice in or near Amsterdam. Because physicians indicated that most patients who refused treatment did not visit them anymore, all Dutch associations for cancer patients were approached. Dutch associations for cancer patients were willing to spread information about the study. Patient members of these associations ($n_{pat}=19$) responded themselves to the call to participate.

Figure 1 Flow-chart of the inclusion of patients for the interview study (n = number of patients; gp = general practitioners; uh = specialists in a university hospital; gh = specialists in general hospitals)



A total of 52 patients were included in the study (30 patients who had refused and 22 patients who had accepted oncological treatment). Inclusion criteria were: being over the age of 18, speaking and understanding the Dutch language, having cancer, having a life expectancy of more than three months (expected prognosis

based on known natural history of a given diagnosis), and having refused or accepted a recommended oncological treatment. All patients recruited by physicians or those who responded themselves from January 2001 until March 2003 were included in the study if they met the inclusion criteria. Both, patients were included who had decided on recommended treatment with higher potential benefit (curative treatment) and patients who had decided on recommended treatment with lower potential benefit (non-curative treatment). Not included were patients who did not respond to the information letter, who indicated that they did not want to participate, who withdrew themselves, or for whom the interview appeared to be too much of a burden.

The study is a matched case-control study, i.e. cases (refusers of treatment) were enrolled followed by controls (acceptors of treatment) who were selected on the basis of similarities to patients in the case group. Selection criteria were: gender, age (± 5 years), and comparable tumour type, stage of disease, estimated prognosis, treatment history, and treatment recommendation.

All patients have been interviewed by one trained interviewer (TvK) either at the patient's home ($n_{pat}=49$) or in the hospital ($n_{pat}=3$). In-depth interview techniques were used. This means that the interviews contained some general topics and no close-ended questions.¹⁶ The interview topics have been formulated on the basis of studies of relevant literature and observations. During the observational studies, 72 patients were observed during their visits to five different oncologists at an oncological outpatient clinic in Amsterdam, the Netherlands. Notes were taken on the reason why the patient visited the oncologist (intake/first visit, control visit after treatment, start/continuation curative treatment, start/continuation palliative treatment), on how a treatment decision was made (initiative by physician, initiative by patient, interaction physician-patient), and on which aspects came up during discussion between physician and patient with regard to treatment (treatment goal, considerations and deliberations of physician and patient). Transcripts from the observations were coded and subsequently the codes were organized into categories and put into a tree-structure. The main categories together with topics from the literature were converted into interview topics. The interview topics of the patient interviews concerned demographic and clinical characteristics of the patient, the course of the disease, communication

with physicians about the recommended treatment, deliberations about the treatment, attitudes of the patient to the recommended treatment, and future perspectives of the patient. To increase objectivity of data analysis, two independent researchers supervised the process of converting the categories of the observational study into interview topics. They underlined important aspects in the transcripts. Subsequently, those aspects were compared with the codes and categories in the analysis performed by the main researcher. Together with topics from relevant literature, this resulted in a topic list. This topic list has been discussed with specialists in the field of research. During the development of the interviews, two pilot interviews were carried out.

In addition to the patient interviews, 16 physicians were interviewed from among the physicians who recruited the patients. Eight general practitioners and eight (general) oncologists were selected, including younger and older, male and female physicians, with few to many years of working experience, and from different settings (general practice, university hospital, and general hospital). The interview topics of the physician interviews concerned characteristics of the physician, working experience, attitudes on curative versus non-curative treatments, and palliative care in oncology, physician-patient relationship especially concerning treatment decisions, treatment refusals and their rationality, patient autonomy, and physician's beneficence. The physician interviews were carried out from May 2002 until October 2002.

All the interviews were audio-taped and transcribed. A descriptive qualitative approach was used to analyse the interviews.¹⁷ During the analysis, computer software based on grounded theory (Kwalitan 5.0) was used for multiple text management, including coding, locating, and retrieving key materials, phrases, and words. Each interview was divided into several segments. The segments were coded and the codes were organized into categories and put into a tree-structure. A second independent researcher supervised this process of data management, i.e. this researcher analysed segments, categorized codes, and analysed this on remarkable aspects. Subsequently, this was compared with the analysis performed by the main researcher. Demographic characteristics have been analysed using SPSS 11.0.

Scope of the thesis

The chapters of this thesis are based on articles, which have been published or have been submitted for publication. Therefore, the various chapters may show some overlap, especially with regard to the Methods sections, which have been maintained in each chapter so that the chapters can be read independently.

Clarification of used terminologies

Chapter 1 starts with a description and a clarification of a generally used, but confusing term in clinical oncology: 'palliative'. Close consideration of the use of the term 'palliative' may clarify the various goals of treatment and care in oncological practice. The different uses of the term 'palliative' in clinical oncology are elaborated and some differences between the goals of palliative care and the goals of palliative oncological treatment are discussed.

Patients' and physicians' considerations

In Chapter 2, the focus is on physicians' evaluations of patients' decisions to refuse oncological treatment. It is described what is meant in daily medical practice by rational decision making. Discussed are questions concerning the following: what do physicians understand by 'good reasons' to refuse recommended oncological treatment, and what motivate patients to refuse treatment and how has this been communicated with their physician.

In Chapter 3, the end-of-life attitudes mentioned by patients who decide on oncological treatments are described. It is discussed whether end-of-life attitudes of patients who refuse oncological treatment differ from those who accept such treatment.

Patient autonomy

In Chapter 4, the concept of patient autonomy is approached from a practical point of view by using empirical data retrieved from the interviews. Focus questions are: (1) what is meant by patient autonomy, i.e. how is this autonomy conceptualized and (2) which factors influence patient autonomy.

Chapter 5 offers a more comprehensive, ethical-philosophical elaboration on patient autonomy. The empirical findings are discussed in relation to the liberal understanding of patient autonomy, to the perspective of an ethic of care, and to the approach of patient-centered medicine. The focus is on (1) patient autonomy as 'making decisions' and 'defining life choices', (2) the idea of freedom that is attached to patient autonomy, and (3) a patients' and a physicians' perspective in medical decision making.

General discussion and summary

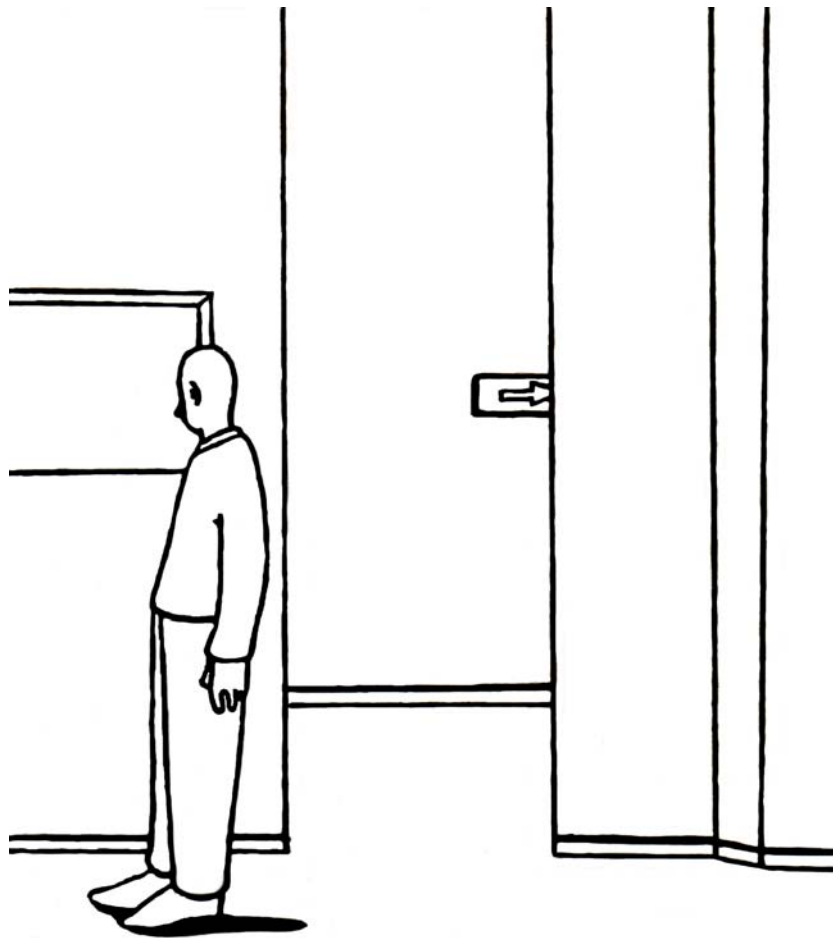
In the general discussion, methodological considerations are given, the results are put into perspective, and the research question is discussed. Finally, the results are summarized. A summary is also given in Dutch.

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Chapter 1

Clarifying the term 'palliative' in clinical oncology



Van Kleffens T, Van Baarsen B, Hoekman K, Van Leeuwen E. Clarifying the term 'palliative' in clinical oncology. *European Journal of Cancer Care* 2004; 13:263-271.

1 Clarifying the term 'palliative' in clinical oncology

The objective of this study was to clarify the term 'palliative' in clinical oncology. A qualitative study design with in-depth interviews was applied. The study sample included 30 cancer patients and 16 physicians.

In clinical oncology, the use of the term 'palliative' to describe both anticancer treatments and palliative care may cause confusion and misunderstanding. Different aspects of palliative care, as expressed by the WHO definition, are not so easily recognizable with regard to palliative oncological treatments. Furthermore, the fact that the same anticancer treatments can be given to patients with palliative or curative intention is confusing. The distinction between curative and palliative oncological treatments is of crucial importance for the treatment decision-making process. Close consideration of the use of the term 'palliative' will help to clarify the various goals of treatment and care in oncological practice.

1.1 Introduction

Developments in medicine, including an increase in palliative options, have led to new approaches to support dying people.¹ One such approach is palliative care, derived from the English Modern Hospice Movement. Cicely Saunders laid down the fundamentals of this movement by founding the St. Christopher's Hospices in 1967.² The approach focused on care for the patient and not solely on the patient's disease. Saunders realized that effective use of morphine could relieve pain and distress, but pain management was not enough to improve the overall care of the terminally ill.¹ She emphasized that pain and symptom management together with the attention for practical and social needs of patients and their relatives shape the care for the dying. Gradually the conviction grew that, especially in the last phase of a person's life, it is extremely important to meet a person in his or her specific questions, wishes, desires and needs. These aspects are to some degree part of the new definition of palliative care, recently formulated by the World Health Organization (WHO).³

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;

- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Before the introduction of the above-mentioned new WHO definition, another description of palliative care was used. That description emphasized its relevance to patients not responsive to curative treatment.^{2,4} Whereas 'not responsive to curative treatment' could be interpreted as relegating palliative care to the last stages of life, the new WHO definition emphasizes that the care is "associated with life-threatening illness". The latter formulation shows that it is recognized that the principles of palliative care should be applied as early as possible in the course of any chronic, ultimately fatal disease.³

According to Porzsolt and Tannock, the explicit statement of the goals of palliative treatments in clinical oncology is very important.⁵ When defining the term 'palliative' related to treatments in clinical oncology, these goals may become clear. Porzsolt and Tannock stated that "the critical end point of anticancer therapies when applied in incurable situations is relief of suffering rather than prolongation of existence".⁵ By using this definition, the term 'palliative' in clinical oncology seems comparable to palliative care as defined by the WHO: "relief from pain and other distressing symptoms" and "intends neither to hasten or postpone death". The goals of palliative treatments in clinical oncology are, however, not always that clear. In the literature, most studies about palliative oncological treatments refer to the definition of Porzsolt and Tannock, but different interpretations have been given. The goals of palliative cancer therapy have, for example, been described as:

- "the alleviation of existing symptoms or the prevention of impending problems"⁶;
- "to prolong the patient's life and to alleviate debilitating symptoms of the disease"⁷;
- "to ensure an optimal quality of life and/or sometimes increase their [patients'] length of survival".⁸

The use of the term 'palliative' in clinical oncology seems to be problematic: confusion and misunderstanding may arise.⁹ Close consideration of the use of the term 'palliative' may clarify the various goals of treatment and care in oncological practice. In this study, we will therefore elaborate on the different uses of the term 'palliative' in clinical oncology. Based on physician and patient interviews, we focus on two aspects. Firstly, we discuss some striking differences between the goals of palliative care as described by the WHO definition and the goals of palliative oncological treatments. Secondly, we try to clarify the term 'palliative' by focusing on the distinction between curative and palliative oncological treatments.

1.2 Methods

The present study is part of a study that aims to clarify the ethical aspects concerning decisions of patients to refuse a recommended oncological treatment, both in a curative and in a palliative setting. The study is based on in-depth interviews with patients and physicians. A qualitative research method has been chosen to elaborate on attitudes and approaches to palliative care and treatments in clinical oncology. Our study was approved by the Medical Ethics Committees of the study sites. All patients gave informed consent.

1.2.1 Participants

Patients who refuse an oncological treatment are difficult to include in a research sample.¹⁰ One reason may be that after their refusal, they withdraw from the medical circuit and are therefore difficult to approach. Another reason may be that patients, after their withdrawal, do not want to be involved in medical research anymore, either because they do not want to be confronted again with hospitals or doctors, or because they are too ill to be interviewed. The patients included in this study form a rather unique sample and deserve our gratitude.

Thirty patients suffering from cancer were interviewed. All of them had refused a recommended oncological treatment. Demographic and clinical characteristics of the patients are given in Table 1. The patients were asked to participate by general practitioners ($n=5$), and by specialists in a university hospital ($n=6$) and in

five general hospitals ($n=2$) in the Netherlands. Dutch associations for cancer patients were willing to spread information about the study. Patients participating in associations ($n=17$) responded themselves for participation.

Table 1 Demographic and clinical characteristics of patients ($n=30$)

	<i>M (range)</i>	<i>n (%)</i>
<i>Age</i>	58 (23-91)	
<i>Gender</i>		
Male		12 (40)
Female		18 (60)
<i>Marital status</i>		
Single/divorced, widowed		13 (43)
Married/registered partnership		17 (57)
<i>Education</i>		
Primary school/lower level high school		9 (30)
Middle level high school		6 (20)
Advanced vocational/university		15 (50)
<i>Cancer diagnosis</i>		
Breast		11 (37)
Gastroenterological		8 (27)
Urological		3 (10)
Gynaecological		2 (7)
Pulmonary		2 (7)
Haematological		2 (7)
Other		2 (7)
<i>Recommended treatment refused</i>		
Chemotherapy		14 (47)
Chemotherapy + radiotherapy		3 (10)
Surgery		3 (10)
Surgery + chemotherapy		4 (13)
Surgery + radiotherapy		3 (10)
Other		3 (10)
<i>What did patient refuse</i>		
All treatment		7 (23)
Part of treatment		23 (77)

Inclusion criteria were: being over the age of 18, speaking and understanding Dutch language, having cancer, having a life expectancy of more than three months, and having refused a recommended oncological treatment. A refusal in this study means that the patient did not start treatment at all, stopped during treatment, or refused a part of a recommended treatment but accepted another

part (e.g. accepted surgery, but refused chemotherapy). All patients recruited by physicians or those who responded themselves from January 2001 until April 2002 were included in the study if they met the inclusion criteria.

Sixteen physicians were interviewed. Physician characteristics are given in Table 2. Of the physicians who recruited patients, a selection of eight general practitioners and eight (general) oncologists was made. To obtain a wide range of different opinions, we included younger and older, male and female physicians, with few and many years of working experiences, and from different settings (university hospital and general hospital). The interviews were carried out from May 2002 until October 2002.

Table 2 Characteristics of physicians (*n*=16)

	<i>M (range)</i>	<i>n (%)</i>
<i>Age</i>	49 (29-60)	
<i>Gender</i>		
Male		11 (69)
Female		5 (31)
<i>Profession</i>		
General practitioner		8 (50)
(General) oncologist		8 (50)
<i>Work experience</i>	18 (2-29)	

1.2.2 Interview procedure

The patient interviews were carried out at the patient's home. Each interview lasted between 60 and 120 min. We used in-depth interview techniques. This means that the interviews contained some general topics and no close-ended questions.¹¹ Interview topics were formulated after studies of relevant literature and observations. Observational studies were performed in order to be introduced in the field of research and to make a first inventory of physician and patient considerations and deliberations regarding treatment decision making. During the observational studies, 72 patients were observed during their visit to five different oncologists at an oncological outpatient clinic in the Netherlands. Notes were taken on the reason why the patient visited the oncologist (intake/first visit, control

visit after treatment, start/continuation curative treatment, start/continuation palliative treatment), on how a treatment decision was made (initiative by physician, initiative by patient, interaction physician-patient), and on which aspects came up during discussion between physician and patient with regard to treatment (treatment goal, considerations and deliberations of physician and patient).

The physician interviews were carried out in the physician's office. Each interview lasted between 30 and 60 min. Interview topics were formulated after literature studies and after analysis of the observational studies and patient interviews. As the physician interviews were carried out after literature studies and after analysis of the observational studies and patient interviews, we were able to discuss themes that were put forward by different perspectives and to gather information on some remaining gaps.

1.2.3 Analysis

Transcripts from the observations were coded and subsequently the codes were organized into categories and put into a tree-structure. The main categories were converted into interview topics. To increase objectivity of data analysis, two independent researchers have supervised the process of converting the categories of the observational study into interview topics. We will give two examples of such a conversion: firstly, the observational studies indicated that among oncologists differences existed in discussing treatment goal. This observation was categorized as 'physician treatment goal'. Subsequently this category was converted into the interview topic 'opinions of palliative and curative care and treatments in oncology' (physician interview). A second example: the observational studies indicated that ideas of patients about treatment goal were sometimes different from those of physicians. This observation was categorized as 'patient-physician interaction treatment goal'. Subsequently this category was converted into the interview topic 'communication with physicians about the recommended treatment and attitudes of the patient to the recommended treatment' (patient interview).

The interview topics of the patient interviews concerned demographic and clinical characteristics of the patient, the course of the disease, communication

with physicians about the recommended treatment and attitudes of the patient to the recommended treatment (with specific attention for communication about and ideas on treatment goal), and future perspectives of the patient.

The interview topics of the physician interviews concerned characteristics of the physician, working experience, opinions concerning palliative vs. curative care and treatments in oncology, physician-patient relationship especially concerning treatment decisions, treatment refusals, patient autonomy, and physician's beneficence.

All the patient and physician interviews were audio-taped and transcribed. A descriptive qualitative approach was used to analyse the interviews.¹² During the analysis, we used computer software (Kwalitan 5.0) for multiple text management, including coding, locating, and retrieving key materials, phrases, and words. Each interview was divided into several segments. The segments were coded and the codes were organized into categories and put into a tree-structure. A second independent researcher has also supervised this process of data management.

1.3 Results

1.3.1 The term 'palliative' in clinical oncology

1.3.1.1 Differences between general practitioners and oncologists

When referring to the term 'palliative', general practitioners in our study referred primarily to palliative care and treatments such as support, relief of pain and symptom management as described by the WHO definition. General practitioners associated palliative care and treatments especially with care for terminal patients.

Physician 1: ... accompaniment of patients (...) a bit of explanation and telling about the disease and further, well, pain management, control of nausea, constipation, that kind of things.

Physician 2: All care for persons who have an incurable disease, who may not recover anymore, thus to be cured from their disease. Thus all measures regarding physical, social, and psychological needs that are imaginable to let life be as qualitatively good as possible, as long as it takes. (...) The majority is of course the care surrounding the end of life.

Oncologists in our study referred both to aspects of palliative care and to treatments as described by the WHO definition, but also to palliative anticancer treatments such as chemotherapy, radiotherapy, or surgery, without any prospect of cure.

Physician 3: There exists a beautiful definition, the WHO definition (...) in essence, all care that will not lead to cure.

Physician 4: Palliative care is both the care you give to the woman with for example breast cancer to whom you give a qualitative good life for 10, 15 years, and the terminal care in hospices.

Physician 5: By palliative care I mean indeed the chemotherapy I give for the greater part.

In this chapter, we will use the term ‘palliative care’ for indicating aspects of palliative care and treatments as described by the WHO definition. For indicating anticancer treatments used in the palliative setting, we will use the term ‘palliative oncological treatments’.

The following differences between these two different approaches of the term ‘palliative’ in clinical oncology could be distinguished.

1.3.1.2 Stage of disease in which care or treatment is provided

According to the WHO definition, palliative care is associated with life-threatening illness. This formulation is meant to show that palliative care should not only be associated with terminal care, but should be applied as early as possible in the course of any chronic, ultimately fatal disease. However, the physician interviews revealed that palliative care is still often associated with pain and symptom management for dying persons. In clinical oncology, it is evident that palliative oncological treatments are provided in all stages of the disease and that these treatments are certainly not associated with patients in the terminal phase. If patients are confronted with a bad prognosis, palliative oncological treatments can be provided in early stages of the disease process.

Physician 3: There are persons who may palliatively react very beautifully and for example can have a few more years, at least according to the expectations.

Physician 6: *For example a patient with breast cancer having a hormone-sensitive tumour. You give her an antihormone and she lives for another 10, 15 years, but it still is a palliative treatment. And we do say that it is [palliative]. From the beginning we call it a palliative treatment, because it will not lead to cure. Eventually they will die because of breast cancer.*

1.3.1.3 Treatment goal: symptom relief

Palliative care provides relief from pain and other distressing symptoms. The physician interviews revealed that palliative oncological treatments are also directed to relieve tumour-associated symptoms. An effective palliative oncological treatment may cause improvement of these symptoms. Besides relieving symptoms, a reduction of cancer volume or stabilization of disease is considered as an important goal of palliative oncological treatments, even though cure is no longer an option.

Physician 1: *When you have constipation in your intestines, because of a tumour, then you can remove that tumour as such that the intestines keep on functioning although it is not a curative operation.*

Physician 7: *That means that you can not totally remove the tumour, but what can be very important for patients for gaining some time and manage the pain. (...) In several cases, it is just the tumour that bothers, that prevents things, that gives complaints. Well, then I have the opinion that if you have a good effective therapy, then that is a very good palliation. You approach the complaints from the source.*

Physician 8: *... it [oncological treatment] is not really directed on cure, well yes, restricting the process (...) to relieve the symptoms whereas there is no curative aspect anymore as such that you try to achieve a remission of the tumour.*

If the tumour mass is reduced by the treatment, alleviation of symptoms may occur until the cancer starts growing again. However, if a treatment is ineffective, existing symptoms may transiently increase. In addition, toxicity as a consequence of the treatment may induce new symptoms, which are acute or sub-acute, reversible or irreversible.

Physician 9: *... that you will otherwise overshoot the mark. Then you just make persons ill with your medicines and things.*

Physician 10: *... but it has a risk when you give chemotherapy. It may cause side effects, it may just happen that you suffer more from the side effects and you can not predict that in advance.*

Physician 7: *I think that chemotherapy can work in the palliative setting, but you have to be very careful, it may work out the wrong way.*

1.3.1.4 Treatment goal: quality of life

Palliative care is an approach that tries to preserve or improve the quality of life of patients. This goal is recognized and experienced by patients.¹³ In line with palliative care, physicians indicated that palliative oncological treatments may also be directed to preserve or improve quality of life.

Physician 8: *It also deals of course with quality of life, handicaps caused by the treatment, that is of course something you have to take care of.*

Physician 5: *... everything you do that has been directed to improve quality of life. That can also be chemotherapy or all sorts of other means.*

Physician 11: *... a variety of measures, and those can be medicinal or non-medicinal, that aim to keep quality of life as optimal as possible, not dealing with cure, but actually preservation of quality or improvement of life.*

Many patients, however, believed that quality of life is incompatible with receiving palliative oncological treatments. More than half of the patients chose not to be treated because they believed that treatments would not result in a better quality of life and would only cause side effects and/or increase or induce symptoms.

Patient 1: *... the quality of life will diminish when you remove a large part of the small intestine.*

Patient 2: *... nevertheless have a fine life, higher quality of life, without chemotherapy.*

Patient 3: *... that I stand at risk due to the "pleasant" radiotherapy of suffering side effects that actually would diminish my quality of life, scared me to bits.*

Patient 4: *... we can postpone death with chemotherapy. But the time of postponement, how will I live then, what is the quality of my life? Thus, I have to give up quality.*

1.3.1.5 Treatment goal: life-prolonging

Palliative care intends neither to hasten nor to postpone death. The physicians in our study stated that, in addition to preserve or improve quality of life, palliative oncological treatments aim to prolong life.

Physician 3: ... *you have decided to catch the possibility for improvement or prolongation of life or improvement of quality or whatever.*

Physician 12: ... *there's no chance of cure, but to keep the duration of life as long as possible with a quality of life as good as possible.*

Life-prolonging is often mentioned as an important reason why palliative oncological treatments are recommended to cancer patients. However, more than half of the patients in our study indicated that they had refused the recommended oncological treatment because for them gaining time did not outweigh the suffering from side effects of treatments.

Patient 5: *As such for me it is a very clear consideration: if I could not really be cured, and it [treatment] is only life-prolonging – and in what way – what kind of a life would I have then, how would I feel, and what would I be able to do?*

Patient 6: ... *“an acceptable investment in life-prolonging”. Well, I don't think so. No, because if it would turn out badly, then I don't want in any case feel continuously ill for the remaining years or have pain somewhere because of treatment, or the consequences of treatment. (...) No, I don't think that is acceptable. I then prefer to die one or two years earlier, but still feeling reasonable.*

Patient 7: ... *I stated in advance that I only want to let these things be done that will not affect my quality of life. Thus, I absolutely don't want that – and chemotherapy would be part of this – for three month you've been miserable, to gain three months of life. Then I would loose in my good time and gain in my bad time.*

The above-mentioned differences between palliative care and palliative oncological treatments are summarized in Table 3.

Table 3 Summary of the differences between palliative care defined by the World Health Organization and palliative treatments in clinical oncology

Palliative Care	Palliative Treatments in Clinical Oncology
<i>Care directed to:</i>	<i>Treatments directed to:</i>
<ul style="list-style-type: none"> ▪ Persons with non-curable life-threatening disease ▪ (Relief of) symptoms ▪ Quality of life, recognized by patients ▪ Neither hastening nor postponing death 	<ul style="list-style-type: none"> ▪ Incurable patients (in all stages of the disease) ▪ Tumour and symptoms ▪ Quality of life, not always recognized by patients ▪ Life-prolonging

1.3.2 The distinction between curative and palliative oncological treatments

1.3.2.1 Clearness of distinction

Our study showed that the goal of an oncological treatment is not always clear to patients. For example, FEC (5-Fluorouracil, Epirubicin, Cyclophosphamide) chemotherapy can have two purposes. On the one hand, (neo-)adjuvant chemotherapy is given to patients with a curative intent. On the other hand, FEC chemotherapy given to patients with metastatic breast cancer has a palliative goal. Surgery for cancer patients is often directed at cure, but in the case of a patient with colon cancer and synchronic liver metastases, the treatment goal is palliative. Radiotherapy is often given with a curative intention in addition to surgery or chemotherapy. However, radiotherapy is also used with a palliative purpose, for example, in the case of bone metastases. From the patient interviews it was established that the fact that the same anticancer treatments can be given to patients with palliative or curative intention may lead to misleading interpretations of the purposes of treatment.

Patient 8: At first, they indicated that they wanted to go for curative treatment. I think that if I had known from the beginning that it was a palliative treatment, I would never have started treatment. (...) As long as you're in that procedure of chemotherapy and appointments to be operated, I had the idea it could be removed. Suddenly you notice that it is not like that.

Patient 9: And I think that it has also been my rescue. I think that if I had not done that [surgery], I wouldn't have been alive today. Especially the first year, you have to be very carefully then. Well, it's almost one year by now, and I assume that I'm cured.

Patient 10: For me it has been used as a support for that chemotherapy, but it is often administered to palliative patients as well. (...) Well yes, if you have a very severe pain, or very serious situations develop as such that they [physicians] can keep it under control, and you will not scream it out loud, may be then it's, but then I know that it's really a palliative treatment and that's not where I am now, I think. (...) I believe, that's the expression for people who can really not be treated anymore with chemotherapy and the process apparently still continues.

Possible misinterpretation of treatment purposes could not only be deduced from the patient interviews. Physicians also recognized that the various purposes of a treatment can be mixed up.

Physician 13: *If something is operable then that seems to be curative. You never know that for sure, because there may always be a metastasis. If that's the case, then immediately it is palliative of course. You're never able to say that in advance.*

Physician 7: *Depending on the goal of the treatment one can say whether a treatment is curative or palliative. This goal can only be clarified by expressing it to the patient. (...) The choice of treatment could be an indication whether the treatment is curative or palliative, but often the same chemotherapy is used for a patient who is treated aiming for cure and for a patient who receives palliative treatment. This is rather unclear for patients.*

Although some physicians expressed that they had no difficulties with indicating if a certain treatment was palliative or curative, other physicians had great difficulties with this distinction and pointed to this separation as a grey area instead of a sharp line.

Physician 1: *That distinction can of course fade away.*

Physician 2: *The distinction between a curative goal of such a treatment and a palliative one is not always sharp. I think it is reality that one not always knows it. (...) There exists a grey area (...) I think one often knows it but there exist doubtful cases.*

Physician 9: *That moment can not always clearly be indicated, but often it can. My experience is that in that case it's often not indicated and that's a pity. It is possible, especially when you are more experienced, then in general it can rather good be indicated.*

Physician 6: *Crystal clear (...) regarding to breast cancer, in the beginning when you operate someone and affected lymphnodes are still present in the armpit, we give adjuvant chemotherapy, as we call it, and that belongs to curative treatment. That kind of chemotherapy is also given for palliative purposes, thus that may get mixed up, but it never causes confusion because it's a totally different phase and the persons who are treated curatively, don't know anything about palliative chemotherapy.*

1.3.2.2 Importance of distinction

Physicians, nevertheless, indicated that it is important to know whether a treatment is curative or palliative and to communicate this to the patient for three reasons:

(a) It is an indication for patients to know in which phase of the disease they are; what their prognosis is.

Physician 9: ... *that you will not unnoticeably plod along as such that the patient keeps on fighting, whereas the fight has already been lost. It would prove very helpful to the patient, when preparing him or herself to the things that are to come, taking care of everything, saying goodbye.*

Physician 3: *Persons are inclined to say that it's going well and put even into words, something I never say, in percentages that they have a very little chance, only one percent, they know exactly in percentages their chances on cure, whereas that's more something that results from their own hope and what they deduce from the success of a palliative treatment.*

Physician 5: *A lot of persons have never realized, that whole period, they were going to die.*

(b) It influences the grade of toxicity of a treatment that is acceptable for the doctor and for the patient.

Physician 3: *Concerning curative treatments you will go farther and accept more side effects than concerning palliative treatments.*

Physician 6: *The curative treatment (...) often is very intensive and generally you will accept a lot of side effects, much toxicity as such that you say, well it's a heavy treatment.*

(c) It strongly influences the extent of pressure physicians will exert to persuade the patient to be treated as recommended. Physicians indicated that they exert more pressure on patients to accept a curative oncological treatment, whereas, if the recommended treatment has a palliative goal, physicians indicated that they exerted less pressure.

Physician 10: *Well, if patients could just really realize what they may be missing, with the treatment they could obtain, if they continue, if they at least know that. Then I could accept it [treatment refusal]. And I'm talking particularly about palliative treatment. As to a cure, I would always be willing to go a bit further and possibly involve some colleagues.*

Physician 12: *Concerning palliative care, you don't have to be insistent, because it's a matter of your obligation to explain it clearly, and then the patient together with his family decides. Concerning a cure, you have to exert pressure. Of course it depends on the chance of a cure.*

1.4 Discussion and conclusion

From hospices and nursing homes, the term 'palliative' has been taken over by other settings, for example the clinical oncological setting. The use of the term

'palliative' in clinical oncology is problematic: confusion and misunderstanding may arise. We argue that the notion of palliative care, represented by the WHO definition, is not applicable as such in clinical oncology.

In line with Porzsolt and Tannock,⁵ our findings emphasize that the use of the term 'palliative' in cancer medicine refers to two approaches: on the one hand, pain control and symptom management as described by the WHO definition ('palliative care'), and, on the other hand, non-curative anticancer treatments such as chemotherapy, radiotherapy, and surgery ('palliative oncological treatments'). Both approaches appear to be mixed up, whereas, as the present study shows, clear differences between the two approaches can be distinguished. These differences include: the moment care or treatments are provided, whether care and treatments are symptom and/or disease directed, the recognition by patients of the goal to preserve or improve quality of life, and the aim to prolong the life of the patient.

In clinical oncology, different terminologies have been used to describe anticancer treatments that are not cure-directed.^{5,14-17} In addition, various definitions have been used to indicate the goals of palliative oncological treatments.⁵⁻⁸ All these definitions emphasize other aspects of the treatment goals. Diversity in treatment goals and effects make the use of the term 'palliative' in clinical oncology disputable. 'Palliative' is sometimes used to indicate less aggressive treatments. Palliative therapy is not always given to ameliorate quality of life or to treat embarrassing symptoms. Instead, patients may be treated with palliative means, while they have no symptoms at all. Patients in advanced stages of their disease, who receive palliative treatment, will in fact encounter additional symptoms (toxicity), and not always only transient. Palliative treatments are initially often associated with worsening conditions (nausea, fatigue, etc.). Furthermore, an initial antitumour response does not always mean an increase in life expectancy. Finally, palliative therapy sometimes means mainly therapy with a low response rate or without complete responses.

Ahmedzai stated that most contemporary views, including the WHO definition, depend on the identification of a 'critical transition' between curative and palliative care.¹⁸ He argued that often no critical moment of transition exists and 'curative' usually means life-prolonging. We observed that, concerning situations in which

patients refuse a recommended oncological treatment, this distinction indeed seems to be problematic. After treatments with palliative intention, sometimes long-survivors have been found, and after therapy with a curative goal patients may die because of progressive or recurrent cancer. Moreover, the same anticancer treatments can be given to patients with palliative or curative intentions, which may be rather unclear for both patients and physicians. Some physicians point to the curative/palliative separation as a grey area. At the same time the distinction between curative and palliative treatment goals is of crucial importance for patients and physicians: it is an indication for patients to know what their prognosis is, it influences the grade of toxicity that is acceptable for the physician and for the patient, and it influences the extent of pressure physicians will exert to persuade patients to be treated as recommended.

The American Society of Clinical Oncology has emphasized the importance of the critical transition point from curative to palliative.¹⁹ They recommend that oncologists must learn to recognize and respond to the transition point in a patient's care "when disease-oriented anticancer therapy must give way to symptom-oriented palliative therapy".¹⁹ We argue that the transition from curative to palliative treatment may be obscured when symptom-oriented palliative treatments are in fact tumour-directed. Often, the doctor knows very well what he or she means using the word palliative (= low or zero chance of cure). However, the word 'palliative' may be interpreted in a more favourable way by patients or their family. The et al., for instance, described the confusion among patients with advanced small cell lung cancer who received tumour-directed chemotherapy, although cure was no longer possible.¹⁵ These patients developed a false optimism about the success of their chemotherapy, because on the X-rays they saw that the tumour vanished. The distance between doctors and patients when interpreting the value of a certain therapy becomes greater when the therapy generates some initial success. The patient may be inclined to see this as a signal towards potential cure – maybe despite earlier warning by the oncologist – whereas the doctor knows that success will be transient mostly, because of acquired resistance.

In clinical oncology, the term 'palliative' is used to indicate non-curative, tumour-directed treatments that may have side effects. The contamination of the

term 'palliative' with the inflicted symptoms of toxicity of oncological treatments and possible worsening conditions of quality of life is problematic. The term 'palliative' is connected with the WHO definition of palliative care, which states that treatment or care is directed to relieve symptoms. If we want to define an oncological treatment as palliative, then side effects endangering quality of life should be avoided. Although a non-curative oncological treatment may be palliative, to forego miscommunication, goals should be called non-curative.

Patients have an interest in knowing whether their oncological treatment has a curative or a non-curative goal. Clarification about treatment goal may also be of crucial importance for communication with other professionals. General practitioners and oncologists are inclined to refer to different interpretations of the term 'palliative'. General practitioners primarily refer to palliative care as described by the WHO definition, whereas a majority of the oncologists refers to palliative anticancer treatments. To forgo miscommunication between professionals from different disciplines, but also within one discipline, we believe that we should not use various definitions of the term 'palliative'. Therefore, we propose to reserve the term 'palliative care' for care that is directed to pain, nausea, fatigue, dyspnoea, diarrhoea, for example, for symptom therapy. When referring to anticancer treatments in the clinical oncological practice, we propose to distinguish between treatments with curative and non-curative goals. The above-described clarifications in the use of the term 'palliative' in clinical oncology may help professionals in their practice and it may serve to forgo miscommunication with patients and other professionals, intra- and interdisciplinary.

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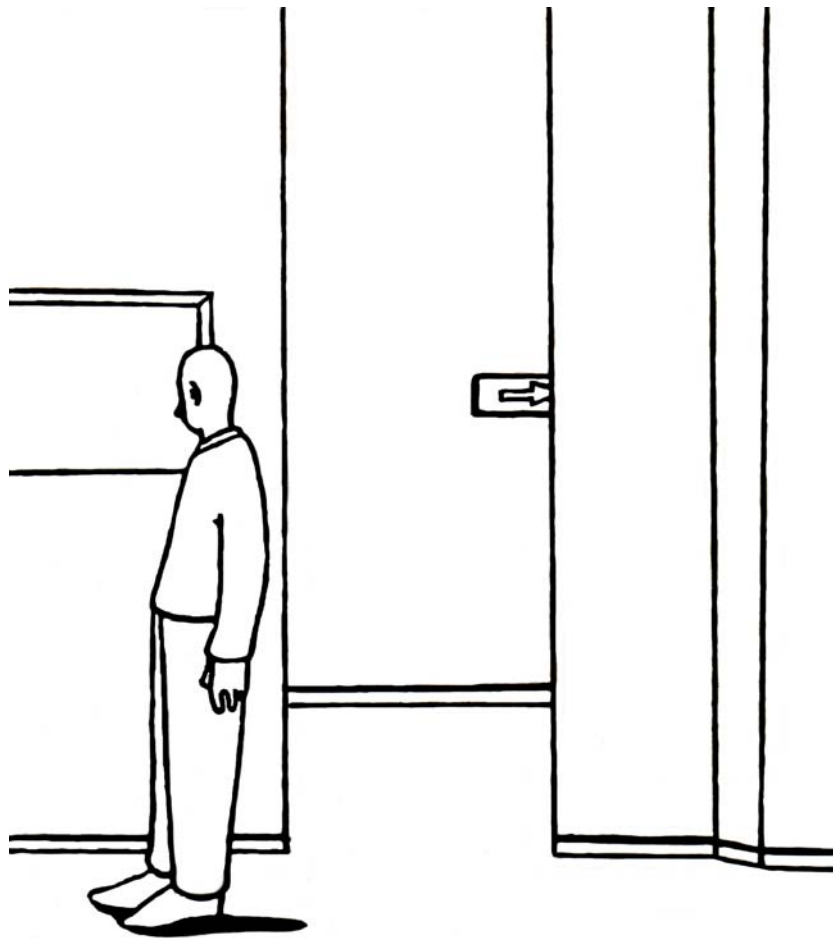
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Chapter 2

Physicians' evaluations of patients' decisions to refuse oncological treatment



Van Kleffens T, Van Leeuwen E. Physicians' evaluations of patients' decisions to refuse oncological treatment. *Journal of Medical Ethics in press*.

2 Physicians' evaluations of patients' decisions to refuse oncological treatment

The objective of the study was to gain insight into the standards of rationality that physicians use when evaluating patients' treatment refusals. A qualitative study design with in-depth interviews was applied. The study sample included 30 patients with cancer and 16 physicians (oncologists and general practitioners). All patients had refused a recommended oncological treatment.

Patients base their treatment refusals mainly on personal values and/or experience. Physicians mainly emphasize the medical perspective when evaluating patients' treatment refusals. From a medical perspective, a patient's treatment refusal based on personal values and experience is generally evaluated as irrational and difficult to accept, especially when it concerns a curative treatment. Physicians have different attitudes towards non-curative treatments and have less difficulty accepting a patient's refusal of these treatments. Thus, an important factor in the physician's evaluation of a treatment refusal is whether the treatment refused is curative or non-curative.

Physicians mainly use goal-oriented and patients mainly value-oriented rationality, but in the case of non-curative treatment refusal, physicians give more emphasis to value-oriented rationality. A consensus between the value-oriented approaches of patient and physician may then emerge, leading to the patient's decision being understood and accepted by the physician. The physician's acceptance is crucial to his or her attitude towards the patient. It contributes to the patient's feeling free to decide, and being understood and respected, and thus to a better physician-patient relationship.

2.1 Introduction

When a patient decides to refuse a recommended oncological treatment, the physician is faced with questions about the background of this decision, the patient's arguments, the acceptability of the decision, and the patient's role in the decision-making process. The physician has to evaluate the patient's decision: is it sensible, responsible, and judicious? Often the evaluation is then directed to the question: is the patient's decision rational or not?^{1,2} The actual standards of rationality in these cases, however, are not clear. The question therefore arises: on what basis do physicians distinguish between their patients' rational and irrational arguments?

In medical-ethical literature, rationality is described in various ways. Rational choice has, for example, been described as the choice that maximizes expected utility or that satisfies the patient's aims and values most.¹ In other cases, having 'good reasons' is at the centre of the evaluation of rationality.²⁻⁴ Savulescu and Momeyer state that "It is rational for a person to perform some act if there would

be a good reason to perform that act if the facts were as he/she believes them to be.”² A pilot study revealed that a physician’s evaluation of the rationality of the patient’s decision is crucial to their attitude towards the patient: if a physician thinks the patient’s refusal is not based on good reasons, he or she is often inclined to consider the decision as irrational and will keep trying to convince the patient to accept the treatment.⁴ The evaluation of ‘good reasons’, however, raises another question: what makes a reason a good reason: ‘good’ in a medical context, ‘good’ in a patient context, or ‘good’ in both?

The purpose of this chapter is to gain insight into the standards of rationality used by physicians. We focus on two aspects of this issue: firstly, we describe what is meant in daily medical practice by rational decision making and discuss what physicians understand by ‘good reasons’ to refuse recommended oncological treatment. Secondly, we discuss what motivates a patient to refuse a treatment and how this is communicated to their physician.

2.2 Methods

The present study is based on in-depth interviews with patients and physicians. All patients had refused a recommended oncological treatment. In this study refusal meant the patient did not start treatment at all; or stopped during treatment; or refused a part of a recommended treatment but accepted another (for example, accepted surgery but refused chemotherapy). A qualitative research method was adopted to explore patients’ deliberations that led to refusal of a recommended oncological treatment and to determine physicians’ evaluations of the treatment refusals. The study was approved by the Medical Ethics Committees at the study sites. All patients gave written informed consent.

2.2.1 Participants

Patients who have refused an oncological treatment are difficult to enrol for a research sample.⁴ One reason may be that after their refusal, they have withdrawn from the medical circuit and are therefore not easy to approach. Another reason may be that after their withdrawal, patients no longer want to be involved in

medical research, either because they do not want to be confronted by hospitals or doctors again or because they are too ill to be interviewed. The patients included in this study form a rather unique sample and deserve our gratitude.

A total of 30 patients (mean age 58 years, range 23-91) were interviewed. Demographic and clinical characteristics of the patients are given in Table 1.

Table 1 Demographic and clinical characteristics of the patients included in the present study ($n=30$)

	<i>n (%)</i>
<i>Gender</i>	
Male	12 (40)
Female	18 (60)
<i>Marital status</i>	
Single/divorced, widowed	13 (43)
Married/registered partnership	17 (57)
<i>Education</i>	
Primary school/lower level secondary school	9 (30)
Middle level secondary school	6 (20)
Advanced professional/university	15 (50)
<i>Cancer diagnosis</i>	
Breast	11 (37)
Gastroenterological	8 (27)
Urological	3 (10)
Gynaecological	2 (7)
Pulmonary	2 (7)
Haematological	2 (7)
Other	2 (7)

The inclusion criteria were: (a) age more than 18 years; (b) able to speak and understand Dutch; (c) having cancer; (d) life expectancy of more than three months; and (e) having refused a recommended oncological treatment. The patients were asked to participate by general practitioners ($n=5$) and by specialists in a university hospital ($n=6$) or in general hospitals ($n=2$) in the Netherlands. Dutch associations for patients with cancer were willing to spread information about the study. Patient members of these associations ($n=17$) responded themselves to the call to participate. All patients recruited by the physicians or those who responded themselves between January 2001 and April 2002 were included in the study if they met the inclusion criteria. We included both patients

who had refused a recommended treatment with higher potential benefit (curative treatment, $n=10$) and patients who had refused a recommended treatment with lower potential benefit (non-curative treatment, $n=20$).

A total of 16 physicians were interviewed from among the physicians who recruited the patients. Eight general practitioners (50%) and eight (general) oncologists (50%) were selected, including younger and older (mean age 49 years, range 29-60), male ($n=11$, 69%) and female ($n=5$, 31%) physicians with few to many years of working experience (mean 18 years, range 2-29), and from different settings (general practice, university hospital, and general hospital). The interviews were carried out between May and October 2002.

2.2.2 Interview procedure

Each patient interview was carried out at the patient's home. Each interview lasted between 60 and 120 minutes. We used in-depth interview techniques, that is, the interviews contained some general topics and no close-ended questions.⁵ The interview topics covered demographic and clinical characteristics of the patient; the course of the disease; communication with physicians about the recommended treatment; the patient's attitude to the recommended treatment; and the patient's perspectives of the future. The interview topics were formulated after examining the relevant literature and undertaking preliminary observational studies. In these studies, 72 patients were observed during their visits to five different oncologists at an oncological outpatient clinic in the Netherlands. From the transcripts, various aspects of the discussion between physician and patient about recommendations for treatment were noted and converted into interview topics.

Each physician was interviewed at his or her office. Each interview lasted between 30 and 60 minutes. The in-depth interview topics covered the characteristics of the physician; working experience; curative versus non-curative treatment and palliative care in oncology; the physician-patient relationship, especially concerning treatment decisions; patient autonomy; physician's beneficence; and treatment refusals and their rationality. At the end of the interview, the medical history of one patient who participated in the study was

presented as a case (see Box 1), and the physicians were asked to give their opinion about the rationality of the patient's decision.

Box 1 The case of Mrs S.

Mrs S. is 54 years old. After a period of fever and pneumonia, she was diagnosed as having bronchial carcinoma (non-small cell lung cancer in the upper right pulmonary lobe). The attending physician recommended surgery in which part of the lung would be removed (lobectomy). Mrs S. decided to refuse the recommended surgery.

Mrs S.: I was afraid, and this fear was based on the mediastinoscopy [a diagnostic procedure carried out behind the sternum in the upper part of the chest cavity, which she recently had undergone, TvK]. I awoke when I was still in the operating room. I think something was not timed very well. A tube was still in my throat. I don't know if the tube was in my trachea or in my throat. I don't know, but I heard someone say that the surgery had been successful. And I was choking, I pulled out the tube and immediately afterwards I was transferred to the recovery room and there, for one and a half hours, I had terrible shortness of breath. I really thought I would suffocate.

At that moment I thought: what if I had to undergo such a lobectomy? Then I would be in intensive care for three or four days. What if I keep getting that suffocating feeling. I know that they may make it technically possible for me not to really suffocate, but the feeling is terrible. I took three days to reflect on that, and then I decided for myself, no surgery. I am afraid. It is fear, fear of the surgery and what may come afterwards.

2.2.3 Analysis

All the patient and physician interviews were audio-taped and transcribed. A descriptive qualitative approach was used to analyse the interviews.⁶ During the analysis, we used computer software (Kwalitan 5.0) for multiple text management, including coding, locating, and retrieving key materials, phrases, and words. Each interview was divided into several segments. The segments were coded and the codes were organized into categories and put into a tree-structure. A second independent researcher supervised the process of data management.

2.3 Results

2.3.1 A medical perspective

Mrs S.'s case (see Box 1) was presented to all the physicians in the study. They were asked whether they would judge her decision as rational or as irrational.

Physician 1: If it is related to previous communication breakdown combined with an enormous amount of fear thus preventing the patient from forming a good idea of what that cancer can do if it is not treated, and no good decisions are made, then I find it irrational. Or at least something I would try to change.

Physician 2: Well, those experiences, if they are based somehow on facts that I can verify, I could find that rational. But when I have the feeling that it is not based on facts, I find it very irrational.

The physician interviews revealed that physicians mainly emphasize the medical perspective when evaluating what are good reasons, and thus, what is rational. This perspective consists of a consistent system of terminologies, deliberations, and expressions that are common in medical practice. The physicians indicated that if a patient's refusal was based on reasons related to the kind of tumour, the prognosis, and/or the side effects of the treatment, they were rather inclined to evaluate these reasons as good reasons and to accept the refusal. Moreover, the physicians felt that rational arguments are related to those reasons that are scientifically proved, such as the chance of the treatment being effective or gaining medical benefit. If a patient refuses oncological treatment because he or she does not want to experience the side effects, a physician judges this decision to be rational if side effects are indeed expected to occur.

Physician 3: If the chance of effectiveness is small and the price one has to pay is high with regard to side effects, I can imagine someone saying, 'It is not worth all the trouble and at this moment I have few complaints, thus why should I?' I find that a rational argument.

A significant factor in the physician's evaluation of a patient's decision is the phase of the patient's disease; the distinction between the curative and palliative phases of the disease and treatment processes plays an important role in a physician's evaluation and acceptance of a patient's refusal for treatment.

Physician 4: *Well, if patients could just really realize what they may be missing, with the treatment they could get, if they continue, if they at least know that. Then I could accept it [treatment refusal]. And I'm talking particularly about palliative treatment. As to a cure, I would always be willing to go a bit further and possibly involve some colleagues.*

2.3.1.1 Curative treatment

The interviews revealed that when a physician thinks there is a reasonable chance of cure, a patient's treatment refusal is often judged as irrational and is difficult to accept for the physician. Physicians evaluate the decision to accept or to refuse a recommended oncological treatment as a decision about life or death: when the patient refuses treatment, he or she chooses for disease progression, with a greater chance of dying from the disease. They consider the decision to refuse curative oncological treatment out of proportion. From a physician's point of view, the consequences of the decision are enormous and cannot be compared with the possible side effects of the treatment. In other words, according to the physician, the benefits are much greater than the price the patient has to pay.

Physician 4: *Those tubes [of Mrs S.], I do not find that rational. It is not such a big problem compared to the fact that she can remain alive. The patient does not see the right relation between the proportions [sic!]. It's like when you say that your cat will be alone for one day, that has no relation to what you can gain from it [treatment].*

Age also seems to play a role in the physician's evaluation of the patient's refusal of curative treatment. Physicians find it easier to accept a treatment refusal by an older patient than a younger patient.

Physician 5: *Concerning chemotherapy, which can also cure the elderly, I can imagine some people would not want that. I would agree to not giving chemotherapy with a curative intention. Concerning young people, I find it hard not to offer curative treatment, because that is simply choosing death. In such cases I am the attending physician who will try to win someone over.*

2.3.1.2 Non-curative treatment

When a physician is of the opinion that cure is no longer an option, the decision of a patient to refuse oncological treatment seems easier to accept compared with

the situation in which there is a reasonable chance of cure. The appropriateness of the decision about non-curative oncological treatment directed at palliation, which includes choices about prolonging life as well as quality of life, is perceived differently from the decision about curative oncological treatment. The consequence of refusing non-curative oncological treatment may be that the patient will die a few months earlier, but it is not a matter of life or death. Physicians are of the opinion that in the palliative phase the most important thing is accurate interpretation of the patient's wishes, and in these circumstances it is the patient who decides what a 'good' palliative phase actually means. The interviews revealed that physicians find the degree of rationality of patients' arguments less important from a medical perspective when it comes to decisions about non-curative treatment compared with decisions about curative treatment: in the palliative phase, the best option for the patient is at the forefront, and this option does not have to be in agreement with the best medical option.

Physician 4: And when that patient just says, 'Well, for me it is not a matter of a long life, I just want a good quality of life and I just want to do some nice things.' Yeah, I find that a very good reason.

Life expectancy seems to play an important role in the physician's evaluation and acceptance of a patient's refusal of non-curative treatment. For example, patients with breast cancer can receive non-curative treatment for a very long time. A patient with a prognosis of a five year palliative phase, could, by her decision to refuse treatment, shorten her life by several years. That decision is much more difficult for a physician to accept compared with a decision about a palliative phase lasting only a few months. In the latter case, refusing oncological treatment could mean that instead of, for instance, six months, the patient's prognosis would be three months.

Physician 6: For some treatments, like for metastasised stomach carcinoma, you wonder whether or not you should carry it [treatment] out. And if patients say, 'I don't want it', I will not say they have to. Regarding breast cancer, I am more inclined to convince patients of the usefulness of the treatment, because there are some very valuable palliative treatments. (...) The tumours respond very well and a very good palliative effect can be attained. As such, the patient's complaints disappear and they will benefit from the treatment for a long time. (...) Concerning breast cancer you will try to convince patients, whereas in stomach cancer you will try but to a lesser degree.

As with refusal of curative treatment, age also seems to play a role in the physician's evaluation of a patient's decision to refuse non-curative treatment, mostly in combination with life expectancy. When it is expected that a recommended treatment will prolong a patient's life for several years, the decision of a younger patient to refuse treatment is more difficult to accept than when an older patient makes the same decision. If the aim of the recommended non-curative oncological treatment is to prolong life by several months, the age of the patient, that is, whether the decision is made by a younger or an older patient, usually does not make a difference to the physician's acceptance of the decision.

To illustrate this point, Mrs S.'s case can be used again as an example. As revealed by our empirical study, if Mrs S.'s decision concerned curative treatment, physicians would find it very hard to accept it: the decision is irrational from a medical point of view since it is very unlikely that she would have the same experience again. If the decision concerned non-curative treatment, physicians would find it easier to accept it, even though Mrs S.'s life expectancy can be prolonged by the treatment. In the latter case, the physician is inclined to place more emphasis on the patient's considerations about fear, experiences, and personal wishes and desires than on whether their arguments are rational or irrational from a medical perspective.

Physician 1: *It is irrational, but for her [Mrs S.] it is reality.*

Physician 7: *Why she [Mrs S.] does it is irrational, but the decision is easy to sympathize with, that's the problem.*

From the last quote, it appears that a physician may sometimes experience problems when evaluating the patient's decision. The physician may judge the patient's treatment refusal as irrational since the decision, from a medical point of view, is not based on good reasons. The decision is based on emotions and on arguments that result from a false impression of things, that is, from earlier experiences of the patient that are not likely to occur a second time. At the same time, however, the same physician may, from a patients' perspective, sympathize with the decision.

2.3.2 The patients' perspective

The reasons why patients refuse oncological treatment are diverse (Table 2). Both medical and personal considerations seem to play a role in the patient's decision to refuse treatment, but personal values and experiences predominate. For example, patients may find it important to occupy themselves – painting, playing tennis, or walking in the mountains. If the side effects of chemotherapy would prevent them from carrying out these activities, the patients in the present study indicated that the meaning to their life would be gone and quality of life decreased. Our empirical study revealed that patients find quality of life to be very important. It was clear that many patients believed that quality of life was incompatible with receiving oncological treatment. More than half chose not to be treated because they believed that treatment would not result in a better quality of life and would only cause side effects and/or increase or induce symptoms. Some patients indicated they would rather live for a little lesser time than prolong their lives with all kinds of troubles due to treatment.

Patient 1: ... my quality of life will diminish when you remove a large part of the small intestine.

Patient 2: ... nevertheless have a fine life, higher quality of life, without chemotherapy.

Patient 3: ... that I risked suffering side effects from the "pleasant" radiotherapy that actually would diminish my quality of life scared me stiff.

Patient 4: ... we can postpone death with chemotherapy. But then, in this period of postponement, how will I live? What will my quality of my life be like? Thus, I have to give up quality.

For some patients with breast cancer, losing a breast plays an important role in their decision to refuse surgery. Such a decision is based on important considerations of the patient's life: keeping her breast may reflect personal values such as identity, dignity, and/or integrity. The importance the patient attaches to her personal values underlies her refusal for treatment, and, apparently, her personal values are so important that she uses them as an argument for a decision that may have far-reaching consequences.

Table 2 Reasons why patients refuse a recommended oncological treatment

- Believe in the body's own curative possibilities
 - Do not want a stoma
 - Do not want to be ill due to the treatment
 - Do not want to be used as a guinea pig
 - Do not want to enter into menopause, still wanting a child
 - Do not want to fight anymore
 - Do not want to lose a breast
 - Do not want to lose hair
 - Do not want to reach old age with dementia, incontinence, and dependency
 - Do not want to spend valuable time in hospital
 - Have accepted death
 - Have a lot to cope with, want to take time to do that
 - Have already reached old age
 - Have fear of treatment
 - Have no trust in treatment/medical establishment
 - Resist chemotherapy; consider it poison
 - Treatment decreases quality of life
 - Treatment will not result in cure, is only life-prolonging
 - Want to continue playing tennis, making paintings, or walking in the mountains
 - Want to stay in control
 - Want to take own responsibility for themselves
 - Want to work on the initial cause of the cancer, not just removing the symptoms
-

As also revealed in the case of Mrs S., patients' personal considerations that underlie a treatment refusal are often based on earlier experiences or on stories and experiences of others. The interviews revealed that most patients referred to their own experience or that of others as a source of knowledge as to what they can expect from being treated or not. These experiences seem to highly inspire patients' decision making.

Patient 5: Besides, two days before I went to my GP, I had buried my friend who had been ill for six years. She had undergone all the standard things and suffered horribly. She was groaning with pain when I visited her at the hospital and I found it just terrible. (...) Afterwards I buried another friend who was also ill for six years. (...) I saw these friends of mine. I saw them suffering. (...) And since I have witnessed and seen all of that, I think well then perhaps just let me go, but don't torture me.

Much of the criticism of patients who refused treatment is related to the fact that treatment is often offered as the 'standard treatment', based on statistics. Our patients indicated that they did not recognize themselves in these statistics. Moreover, they found it important to be approached as individuals.

Patient 6: *I think, you can say whatever you like, but of course for them I am only a case. And they apply a lot of statistics to it. 'If we do that, this will happen and so many will survive. If we don't do that, so many will die.' I think, that's not how it works. I am an individual, I have my history, I have all different kinds of perspectives.*

When offered treatment as the 'standard treatment', some patients feel they are not given sufficient room to reflect on the recommended treatment. Personal considerations, based on norms and values to which they attach great importance, are not allowed to play a role.

Patient 7: *You have to get the chance, I think, as a human being, to be allowed to reflect on it [treatment], to consider what are the consequences and decide only then whether or not you can or want to do it. At that time, that was absolutely not the case. That was it, that was standard. (...) But a patient with cancer is his own "hands-on" expert and physicians have to pay much more attention to what the patient himself experiences. They can learn a lot from their patients, like trying not say, 'This is the European standard, these things make up the treatment and that's what you have to do.'*

2.4 Discussion and conclusion

Our study revealed that when patients decide to refuse a recommended oncological treatment, the physician's perspective may not concur with the patient's perspective. Only few studies have investigated the reasons why patients opt for or against treatment. According to Fried et al., the burden of treatment, the outcome, and the likelihood of the outcome all influence patients' treatment preferences.⁷ Slevin et al. described how patients make a cost-benefit assessment of chemotherapy before opting for or against radical treatment. Chance of a cure, prolonging life, and relief of symptoms were weighed.⁸ Siminoff and Fetting investigated factors affecting treatment decisions in the case of breast cancer. They found that patients who did not accept their physician's treatment recommendation weighed benefits of treatment against the probability and severity of side effects.⁹ Studies examining the type of trade-offs patients with early breast cancer make between benefits and side effects reveal that women with milder side effects (less toxicity) judged smaller benefits worthwhile and that small improvements in survival were sufficient to make adjuvant chemotherapy worthwhile.^{10,11} In addition to weighing improvements in survival and side effects,

women with dependants and social support judged smaller benefits worthwhile.¹⁰ Our results show that a patient's decision to refuse recommended oncological treatment is not particularly based on weighing the pros and cons of treatment from a medical perspective. The decision relies, in particular, on personal values and/or experiences, which seem not to be based on a general moral point of view but seem to have a circumstantial basis, that is, the patient takes his or her own situation, at this very moment, as a starting point.

From both the medical perspective and the patient's perspective, good reasons can be given for refusing oncological treatment. The two perspectives may overlap to some extent, but large parts may not concur. Patients' treatment decisions, which are based on personal values or experiences, most of the time fall outside a medical perspective and are judged by physicians as irrational. The meaning and use of the term 'rationality' from a medical perspective and from a patient's perspective can in our view be described by using the terms 'goal-oriented rationality' ('zweckrationalität') and 'value-oriented rationality' ('wertrationalität') as distinguished and defined by Max Weber.¹² Goal-oriented rationality is directed at effects considering a certain goal. It is part of instrumental rationality; the effectiveness of the relation between means and ends is most important. Value-oriented rationality is not directed at effects, but at a system of values. In our view, the distinction between a medical perspective and a patient's perspective is based on physicians mainly using goal-oriented rationality. Physicians have means (medical treatment) to reach a goal (cure the patient, prolong survival, or improve the quality of life). They weigh the costs and benefits of medical treatments, they opt for the best treatment, and they want to use this treatment to help the patient. However, physicians also seem to use value-oriented rationality, for example, a patient who refuses a medically advisable treatment runs against the physician's feeling of doing well. Similarly, patients also seem to use goal-oriented rationality but to a lesser degree. They do consider advantages and side effects of treatment, but concerning treatment refusal, they mainly use a system of values, that is, they use value-oriented rationality. Thus, both seem to use value-oriented as well as goal-oriented rationality but physicians put more emphasis on the latter and patients on the former. Moreover, physicians'

value-oriented rationality is based on a general moral point of view (for example, doing well), and patients' value-oriented rationality has a circumstantial basis.

Nowadays, it is clearly established in medicine, ethics, and law that a competent patient has the right to refuse medical treatment. There is no difficulty if a patient's refusal concurs with clinical evaluation, but the issue becomes problematic when a patient's refusal conflicts with medical opinion.¹³ Physicians interpret decisions conflicting with medical opinion mostly as irrational, and irrational decisions are difficult to accept. When the patient expresses a non-rational preference, physicians face a dilemma between their duty to care for a patient and respect for patient autonomy, that is, the personal choice of the patient. A physician may try to convince their patient to agree with the doctor's viewpoint by discussing medical facts to ensure that the patient understands his or her situation. Coercive methods to force the patient to agree, however, easily lead to miscommunication and abandonment of the patient.

We argue that the issue is less problematic if physicians interpret 'good reasons' to refuse a recommended oncological treatment from both the medical and the patient's perspective based on specific values. This already occurs in the case of non-curative treatment. Physicians find it less difficult to accept a patient's treatment refusal of a non-curative treatment even if the refusal is, from a medical perspective, based on irrational grounds. Then the physician seems to place more emphasis on the patient's value system. When a physician attempts to see the patient's perspective, this may be enhanced by discussing the physician's and patient's value-oriented rationality in such a way that the circumstantial basis of the patient's decision is understood. Respecting the patient's perspective in the acceptance of treatment refusal is important for the physician-patient relationship. The physician's acceptance is crucial to his or her attitude towards the patient: if a physician does not accept the treatment refusal, he or she is often inclined to persist in convincing the patient to accept the treatment.⁴ This results in patients experiencing that they are not really free to make their decisions, leading to frustration and miscommunication.¹⁴ If a physician does accept a patient's treatment refusal, this will contribute to the patient's feeling of being free to decide, to be understood and respected in his or her decision, and thus contribute to a better physician-patient relationship.

2.5 Acknowledgements

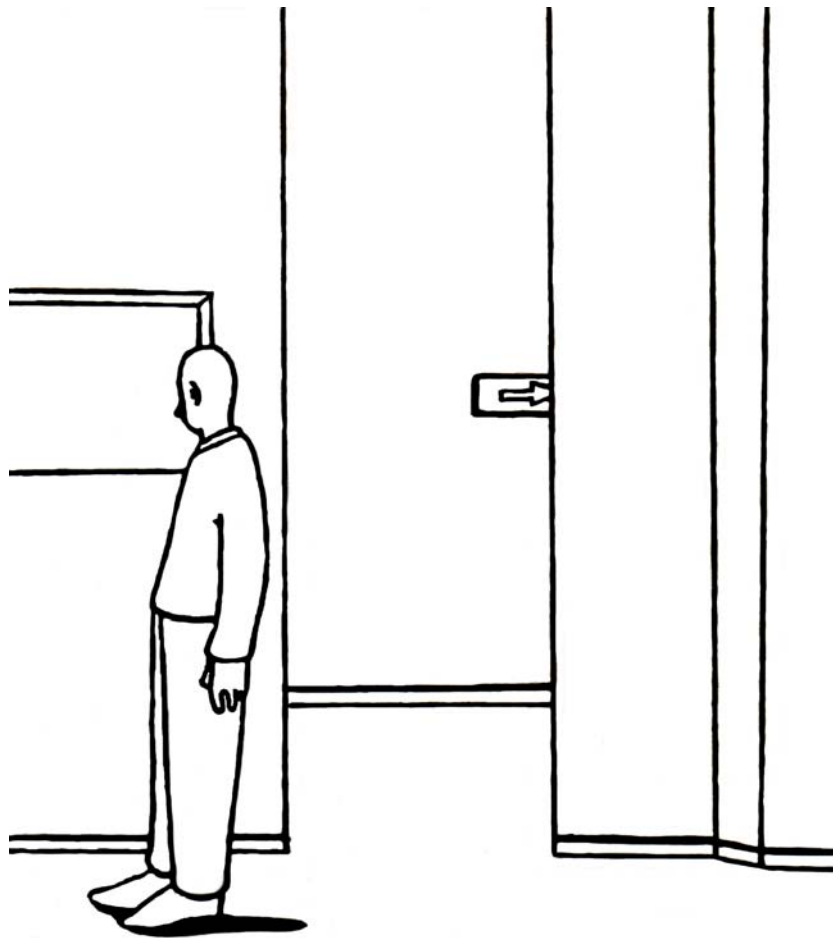
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Chapter 3

End-of-life attitudes of patients who decide on oncological treatment



Van Kleffens T, Van Baarsen B, Van Leeuwen E. End-of-life attitudes of patients who decide on oncological treatment. *Submitted*.

3 End-of-life attitudes of patients who decide on oncological treatment

Patients' decisions on accepting or refusing oncological treatment are influenced by several factors. A factor that needs more understanding concerns the end-of-life attitude of the patient. We discuss patients' attitudes regarding death and dying in relation to their treatment decision.

Thirty patients who refused and 22 patients who accepted oncological treatment were interviewed using in-depth interviews.

Seven end-of-life attitudes were distinguished: fighting death, avoiding death, fearing death, fearing dying, making (funeral) arrangements, controlling death, and accepting death. A majority of the patients who had refused treatment also accepted death. They particularly focused on the end of their life. A majority of the patients who had accepted treatment fought against death or avoided death. They focused on how to stay alive and how to define life choices. They regarded their treatment as life-prolonging and death-postponing. Having a social network seemed to be important in accepting treatment. Accepting or refusing treatment appeared not to be related to fear of death or fear of dying. A desire for euthanasia, however, appeared to be related to fear of dying. Both patients who refused and who accepted treatment mentioned euthanasia. Patients desired euthanasia because they wanted to stay in control and did not want to be dependent on physicians.

Acceptance or refusal of oncological treatment corresponds to different end-of-life attitudes of patients. Knowledge of the end-of-life attitude of a patient in an early stage of disease may help physicians to understand patients' decisions regarding oncological treatment.

3.1 Introduction

In recent years, patients have tended to move toward an active role in making decisions about their medical treatment.¹⁻⁴ In today's health care, patients are even expected to be involved in decisions about their medical care.⁵ Although the majority of cancer patients accepts primary treatment recommendations, patients sometimes refuse recommended oncological treatment. Only a few factors are known concerning the influences on the patients' treatment decision-making process. Silvestri et al. described how patient decision making is influenced by physicians' recommendations, faith in God, ability to cure, side effects, and the input of relatives.⁶ Furthermore, Slevin et al. stated that having a terminal illness causes a shift in attitude in favour of aggressive treatment: patients with cancer are much more likely to opt for radical treatment with minimal chance of benefit than people who do not have cancer.⁷ Weeks et al. studied the influence of prognosis on the choice in favour of certain treatments. They concluded that

patients who believe that they will survive for at least six months favour life-extending therapy over comfort care more than those who believe that there is a chance that they will not live six months.⁸ In our study, we observed that patients' earlier experiences and experiences of close others influence the treatment decision-making process. Those experiences appeared to be a source of knowledge of what can be expected from being treated or not.⁹

In literature, another factor that is suggested to be related to patients' decision making concerns the end-of-life attitude of the patient. Quill, for example, mentioned a case of a woman with acute myelomonocytic leukaemia who refused treatment.¹⁰ Quill concluded: "it was extraordinary important to [this woman] to maintain control of herself and her own dignity during the time remaining to her. When this was no longer possible, she clearly wanted to die". Quill reported that the woman indeed committed suicide. The case reflects an interesting subject that needs more investigation: patients' attitudes regarding death and dying in relation to the decision to accept or refuse recommended oncological treatment. In this chapter we focus on two aspects: firstly, we describe the end-of-life attitudes as mentioned by patients after they had decided to accept or to refuse oncological treatment. Secondly, we deal with the question whether or not the end-of-life attitudes differ in correspondence with accepting or refusing treatment. In the end we pay attention to treatment decisions related to a desire for euthanasia. In the Netherlands, euthanasia is a legally accepted option as a last resort at the end of life.

3.2 Methods

The present study is based on in-depth interviews with patients. The patients had either refused or accepted recommended oncological treatment. In this study, refusal means that the patient did not start treatment at all, stopped during treatment, or refused a particular part of a treatment while accepting other parts (for example, accepted surgery, but refused chemotherapy). The deliberations of patients that led to refusal or acceptance of recommended oncological treatment have been explored using qualitative research methods. Our study was approved

by the Medical Ethics Committees of the study sites. All patients gave written informed consent.

3.2.1 Participants

Patients who refuse oncological treatment are difficult to include in a research sample.¹¹ One reason may be that after their refusal, they withdraw from the medical circuit and are therefore difficult to approach. Another reason may be that after their withdrawal, patients no longer want to be involved in medical research, either because they do not want to be confronted again with hospitals or doctors, or because they are too ill to be interviewed. The patients included in this study form a rather unique sample and deserve our gratitude.

Physicians have approached 47 patients. Thirty-three of these patients were included in the study (response rate 70%). Patients were asked to participate by general practitioners ($n_{pat}=5$), and by specialists in a university hospital ($n_{pat}=25$) or in five general hospitals ($n_{pat}=3$) in the Netherlands. Because physicians indicated to believe that most patients who refuse treatment do not visit them anymore, all Dutch associations for cancer patients were approached. Dutch associations for cancer patients were willing to spread information about the study. Patient members of these associations ($n_{pat}=19$) responded themselves to the call to participate. The fact that a number of patients were obtained from associations for cancer patients may suggest that the patients in the study are not representative of the population of patients with cancer. However, most of the patients became acquainted with the associations only after they had decided about the oncological treatment. Thus, most patients were not members of the associations while they made their treatment decision. Our study focuses on this decision-making process.

A total of 52 patients were interviewed. Inclusion criteria were: being over the age of 18, speaking and understanding the Dutch language, having cancer, having a life expectancy of more than three months (expected prognosis based on known natural history of a given diagnosis), and having refused or accepted recommended oncological treatment. All patients recruited by physicians or those who responded themselves from January 2001 until March 2003 were included in the study if they met the inclusion criteria. Not included were patients who did not

respond to the information letter, who indicated that they did not want to participate, who withdrew themselves, or for whom the interview appeared to be too much of a burden.

The study is a matched case-control study, i.e. cases (refusers of treatment) were enrolled followed by controls (acceptors of treatment) who were selected on the basis of similarities to patients in the case group. Selection criteria were: gender, age (± 5 years), and comparable tumour type, stage of disease, estimated prognosis, treatment history, and treatment recommendation. Two patients who had refused oncological treatment other than for breast or gastroenterological cancer could not be matched because they had a rare combination of a particular tumour type with age and treatment recommendation. One extra patient with gynaecological cancer was included to reach data satisfaction. This resulted in 30 patients who had refused treatment (mean age 53 years, range 20-79) and 22 patients who had accepted oncological treatment (mean age 58 years, range 23-91, Table 1).

We included both patients who had decided about treatment with higher potential benefit (curative treatment, $n_{pat}=17$) and patients who had decided about treatment with lower potential benefit (non-curative treatment, $n_{pat}=35$). Patients who had decided about adjuvant therapies (mostly in the case of breast cancer) were categorized in the curative treatment group. Although a treatment decision on adjuvant therapy seems not so much comparable with a decision on, for example, curative surgery, taking perceived prognosis into account, our study revealed that a treatment decision on adjuvant therapy is better comparable with a treatment decision on curative treatment than with a decision on non-curative treatment.

Patients recruited by physicians were offered treatments with goals determined by the medical information given by the attending physician. For patients who responded themselves to the call to participate, treatment goals were determined by an independent oncologist and by information from the handbook of oncology.¹² In our study, for distinguishing different patient groups, we did not take the patient's prognosis into account, because no reliable prognostic indicators are available. Instead, we distinguished between the goals of the recommended treatments (curative or non-curative). Patients who are facing a cancer diagnosis

with curative opportunities may respond differently to their treatment recommendation and may have different end-of-life attitudes than patients with non-curative opportunities. Therefore, four patient groups were distinguished: patients who refused curative treatment (Rc, $n_{pat}=10$), patients who refused non-curative treatment (Rnc, $n_{pat}=20$), patients who accepted curative treatment (Ac, $n_{pat}=7$), or patients who accepted non-curative treatment (Anc, $n_{pat}=15$).

Table 1 Demographic and clinical characteristics of patients who refused curative treatment (Rc, $n_{pat}=10$), who refused non-curative treatment (Rnc, $n_{pat}=20$), who accepted curative treatment (Ac, $n_{pat}=7$), and who accepted non-curative treatment (Anc, $n_{pat}=15$). Rt = total refusal-group ($n_{pat}=30$); At = total acceptance-group ($n_{pat}=22$)

	Treatment Refused				Treatment Accepted			
	Rc	Rnc	Rt	(%Rt/%total)	Ac	Anc	At	(%At/%total)
<i>Gender</i>								
Male	1	11	12	(40/23)	1	9	10	(45/19)
Female	9	9	18	(60/35)	6	6	12	(55/23)
<i>Race</i>								
White Dutch	9	19	28	(93/54)	6	15	21	(95/40)
Other	1	1	2	(7/4)	1	0	1	(5/2)
<i>Marital status</i>								
Single/divorced, widowed	7	6	13	(43/25)	1	2	3	(14/6)
Married/registered partnership	3	14	17	(57/33)	6	13	19	(86/37)
<i>Children</i>								
No	2	3	5	(17/10)	3	2	5	(23/10)
Yes (independent)	6	12	18	(60/35)	2	6	8	(36/15)
Yes (dependent)	2	5	7	(23/13)	2	7	9	(41/17)
<i>Grandchildren</i>								
No	7	12	19	(63/37)	5	10	15	(68/29)
Yes	3	8	11	(37/21)	2	5	7	(32/13)
<i>Education</i>								
Primary school/lower level high school	5	4	9	(30/17)	3	3	6	(27/12)
Middle level high school	2	4	6	(20/12)	2	5	7	(32/13)
Advanced vocational/university	3	12	15	(50/29)	2	7	9	(41/17)
<i>Cancer diagnosis</i>								
Breast	6	5	11	(37/21)	4	3	7	(32/13)
Gastroenterological	1	7	8	(27/15)	0	5	5	(23/10)
Urological	1	2	3	(10/6)	1	1	2	(9/4)
Gynecological	0	2	2	(7/4)	1	2	3	(14/6)
Pulmonary	0	2	2	(7/4)	0	1	1	(5/2)
Hematological	1	1	2	(7/4)	1	1	2	(9/4)
Other	1	1	2	(7/4)	0	2	2	(9/4)

3.2.2 Interview procedure

All patients have been interviewed by one interviewer (TvK) either at the patient's home ($n_{pat}=49$) or in the hospital ($n_{pat}=3$). Each interview lasted between 60 and 120 minutes. We used in-depth interviews. This means that the interviews contained some general topics and no close-ended questions.¹³ The interview topics have been formulated on the basis of studies of relevant literature and observations. During the observational studies, 72 patients were observed during their visits to five different oncologists at an oncological outpatient clinic in the Netherlands. Notes were taken concerning the reason why the patient visited the oncologist (intake/first visit, control visit after treatment, start/continuation curative or palliative treatment), about how a treatment decision was made (initiative by physician or patient, interaction physician-patient), and about the aspects coming up during the discussions between physician and patient with regard to treatment (treatment goal, considerations and deliberations of physician and patient).

Transcripts from the observations were coded and the codes were subsequently organized into categories and put into a tree-structure. The main categories were converted into interview topics. To increase objectivity of data analysis, two independent researchers supervised the process of converting the categories of the observational study into interview topics. The interview topics concerned demographic and clinical characteristics of the patient, the course of the disease, communication with physicians about treatment, deliberations about treatment, attitudes of the patient to treatment, and future perspectives of the patient.

3.2.3 Analysis

All the patient interviews were audio-taped and transcribed. A descriptive qualitative approach was used to analyse the interviews.¹⁴ During the analysis, we used computer software based on grounded theory (Kwalitan 5.0) for multiple text management, including coding, locating, and retrieving key materials, phrases, and words. Each interview was divided into several segments. The segments were coded and the codes were organized into categories and put into a tree-structure.

A second independent researcher supervised this process of data management. To define which end-of-life attitudes patients who decided on oncological treatments mention, we analysed all the interviews on phrases about the end of life. This resulted in over 130 different end-of-life codes. These codes could be organized into seven categories. These seven categories reflect the seven end-of-life attitudes that have been distinguished in the study.

Demographic characteristics have been analysed using SPSS 11.0. Although we strived for comparability of the two patient groups (At and Rt), comparing the two groups needs caution. Frequencies are given when presenting demographic characteristics of the two patient groups and not significances. For analyses within the groups (Rc-Rnc) and for analyses of the seven end-of-life attitudes, significances are given using χ^2 -tests and t-tests. Although these analyses need also be approached with caution, because some patients were classified in more than one of the seven end-of-life attitude categories, these analyses were helpful to indicate how to interpret the results.

3.3 Results

3.3.1 Treatment decision and demographic characteristic

Between groups

Of the patients who accepted treatment (At, $n_{pat}=22$, Table 1), 86% were married or had a registered partnership, 41% had dependent children, and 36% had independent children compared to respectively 57%, 23%, and 60% of the patients who refused treatment (Rt, $n_{pat}=30$).

Within groups

In the refusal-group (Rt), we observed that chemotherapy was the most refused treatment (70%). Furthermore, we observed that in the Rt-group, 67% refused non-curative treatment (Rnc) and 33% refused curative treatment (Rc). Curative treatment was refused by 50% of the women compared to 8% of the men ($\chi^2=5,625$ (df=1), $p<0,05$) and by a minority (18%) of the patients who were

married or had a registered partnership compared to 54% of the single, divorced, or widowed patients ($\chi^2=4,344$ (df=1), $p<0,05$).

3.3.2 End-of-life attitudes

In the interviews, seven end-of-life attitudes could be distinguished. With end-of-life attitude we mean the way patients deal with, and think and feel about the end of life. Categories were not mutually exclusive, in other words, some patients were categorized in only one of the seven end-of-life attitudes, whereas others were categorized in more than one end-of-life attitude. We illustrate every end-of-life attitude with one quotation of a patient from each patient group (Rc, Rnc, Ac, Anc). The number of quotations (one per patient group) is not representative for the number of patients per patient group classified in a specific end-of-life attitude category.

(a) *Fighting death*. Patients who did not want to give up hope, who wanted to fight for their lives, who fought to stay alive for their children and/or partner, who did not want to rest till they knew they had done everything they could to postpone death.

Patient 1 (Rc): *I just wanted to do everything to survive, for my child.*

Patient 2 (Rnc): *I did not want to die. No, I fought, I kept fighting. I thought, we will see where it all will end.*

Patient 3 (Ac): *I just want to live as long as possible, I mean I've got a nine-year-old son (...) I mean, that boy can't live without his mother, and I have a husband who never wants to lose me.*

Patient 4 (Anc): *It's obvious that it is like that, that it [disease] will be terminal, but you never know. So I won't give up hope. I continued to hold on to that experimental treatment.*

(b) *Avoiding death*. Patients who did not want to think of or want to talk about death and dying, who avoided or denied the subject, who kept busy with living and making future plans, who thought they were not going to die, whether or not their disease was curable.

Patient 5 (Rc): *I just live, and that's all, nothing more. I live day by day. No, that [dying] is not something I think of. Well yes, if it is to happen, then it happens. But like I am at this moment, I just do not think of it.*

Patient 6 (Rnc): *That's not a nice thing to hear and that makes you think, 'Well, yes, but that won't happen to me, that I'm going to die of that disease, that won't happen to me, that is just not possible.' (...) But just, that you still have the idea that this is not how it feels for me. No, and that's what you try to keep in mind, the feeling deep inside, that it's not like that.*

Patient 7 (Ac): *I've not ... no, not really thought about dying from this disease. But I also have the idea that I can't die from it, from cancer, that you can't die from it. I think that happens when, for example, you have it in your brains or something like that.*

Patient 8 (Anc): *I have to tell you that I have questions to which he [physician] gives a fine answer, but that I also bury my head in the sand. I'm not going to ask how long I still have to live or something like that, because exactly these things I do not want to hear.*

(c) *Fearing death.* Patients who were afraid of the finality of death, who were afraid of leaving behind their loved ones and the grief these loved ones might endure.

Patient 9 (Rc): *I was so afraid, so nervous, so with the feeling that I was going to die. I do fight, but I've had a lot of fear. (...) There was one exercise: recognize your own death. That I didn't dare. I pushed away that exercise, pushed away, I found that so unpleasant.*

Patient 10 (Rnc): *I'm afraid of death. I do not want to die. I find it very sad and absolute. (...) I think it is just that the candle has been blown out, there is nothing left, no consciousness, no soul or mind.*

Patient 3 (Ac): *When I feel ill, then I'm very afraid of death. I just find, I just find that J [son] cannot and may not miss his mother yet. Thus, I find that the worst thing, for him.*

Patient 11 (Anc): *[With death] I cannot cope (...) I want to have support for that, because I don't know what to do. (...) At that moment, the children were the decisive factor in saying, 'I can't quit now, I can't say just leave it.' (...) I saw my children and I saw my husband and I thought I have no choice, I have to [undergo treatment].*

(d) *Fearing dying.* Patients who were afraid of the dying process, the pain, and the suffering, who feared a slow process and losing control of organs, who feared losing dignity.

Patient 12 (Rc): *I've thought about how it would be to be terminally ill, to be bedridden. And I think that I can handle that, except for having a terrible lot of pain or being incontinent, as such that I have the feeling that I lose my dignity. And I'm not sure whether it is dignity or that it is the feeling of not having control of my organs as I would like to have.*

Patient 13 (Rnc): *For me, being death is just being death. (...) And I just accept that. (...) Actually I only have fear of that slow process.*

Patient 3 (Ac): *When I'm feeling very ill, then I think, 'Well, is this the beginning of the end?' Is this how it will continue or will I feel better in a few days. And when I think of dying, then I'm also very afraid. The suffering is where I'm afraid of, that appears to me as something terrible. Then I see myself laying in bed and racked with pain. No, that seems terrible to me.*

Patient 8 (Anc): *What I am afraid of is that final part towards death. That I'm not groaning with pain or whatever. That it will be a very decent part.*

(e) *Making (funeral) arrangements.* Patients who prepared their own funeral, who discussed their preferences regarding funeral, grave, and inheritance with their partner and/or children, who laid down arrangements with, for instance, the notary.

Patient 12 (Rc): *When I heard I had cancer, I started to make plans and concretized this by starting to make a list of all persons who, if I would die, should receive a death announcement.*

Patient 14 (Rnc): *The first thing I set to work on was the whole business around the funeral. I already have finished that. I have all arranged that, I do not have to think about that anymore. I have selected a grave. Well, just the fact that I do not have to think about that anymore. (...) I am just finishing my life. I have designed my own death announcement and I have pre-printed it. Sinister but true.*

Patient 15 (Anc): *I've put down everything on paper, I've written down everything. I've consulted my children, I've arranged everything for the children, I've sorted out everything concerning retirement pays, I've phoned everybody. As such that it is all arranged, that they [family] will not encounter any surprises anymore.*

(f) *Controlling death.* Patients who had discussed with their physician, partner, and/or children their wish to stay in control during the last trajectory, who had discussed their preferences for euthanasia, who indicated not wanting to suffer longer than necessary, and who wanted to conduct their own death.

Patient 16 (Rc): *And I have also immediately arranged the euthanasia-certificate. (...) I want to choose by myself. If it would all go wrong, that I want to choose the moment when, for me, it is not acceptable anymore. That is something I have to decide.*

Patient 14 (Rnc): *I have letting formulated a euthanasia-certificate, I asked for a non-treatment card. I have them here in my house. My wife knows more or less what I do and do not want and I also consulted my general practitioner. (...) If I am on a drip with morphine and that doesn't help anymore, and I'm screaming out of pain, then for me it doesn't need anymore. (...) What does it make sense. It would only mean that it's getting worse and worse and then it's finished. Well, then I don't see why I should scream here for two more months.*

Patient 17 (Ac): *And if I'm getting a lot of pain, I just want to have the choice to say, 'It's been enough.' I've talked with my husband and he knows that at that moment I'm not going to find out all kind of things.*

Patient 18 (Anc): *At a certain moment you think, nice and peacefully fall asleep or something like that. We also directly went to the general practitioner to talk with him about euthanasia. (...) I want to have a voice in what is going to happen, I want to have this till the end, that's why I talked about euthanasia.*

(g) *Accepting death.* Patients who were aware of the finality of life, whether or not their disease was incurable, who accepted death to come, who were finishing their lives, who felt they may yield to death.

Patient 19 (Rc): *Yeh, you have to live with it. You're getting old, and you know it [that you're going to die]. I think, just face it!*

Patient 13 (Rnc): *I had the feeling that saying 'no' to CPT11 [chemotherapy] was a kind of accepting death. (...) When I decided about CPT11, I thought, how strange, it seems as if I said to the death, at least that is how I experienced it, that you will die, because you do not take that medicine anymore. Like I have to take that medicine, if you want to live you have to take it, and if you want to stop living, you do not take it.*

Patient 20 (Ac): *I'm not afraid of it. I'm not afraid of dying. Everybody is going to die, and when, we will see.*

Patient 18 (Anc): *That [dying] is the first thing you accept, thus I haven't got so much troubles with that.*

3.3.3 End-of-life attitudes and treatment decision

Of the patients who refused treatment ($n_{pat}=30$, Table 2), 13% could be classified as 'fighting death', 27% as 'avoiding death', and 53% as 'accepting death' compared to respectively 41%, 50%, and 23% of the patients who accepted treatment ($n_{pat}=22$). Significant differences could be observed between accepting and refusing treatment regarding the end-of-life attitudes 'fighting death' and 'accepting death'. Regarding 'avoiding death', a trend could be observed.

The interviews showed that certain factors related to end-of-life attitudes influenced patients' treatment decision making: most patients who accepted treatment did not so much focus on what the end of life would be, like they focused rather on how to stay alive and how to define life choices. They were busy with life, they wanted to enjoy life as long as it would take, and they said not to be ready to

die yet. They accepted treatment because the treatments were thought to be life-prolonging and death-postponing.

Patient 3 (Ac): *You just want to live as long as possible.*

Patient 21 (Anc): *That possibility, yes you do seize that with both hands, to frolic around here on earth a little bit longer. (...) Everybody is going to die at a certain moment, but I do not want to die on the age of sixty-three.*

Patient 22 (Anc): *Actually, I wanted to become healthy again. I was not yet ready to die. (...) It was just like; I was not yet ready for it. It is just like; you have the possibility, use it [treatment]!*

Patient 23 (Anc): *I do not think too much in years. In the past I thought, hopefully I will still be here next year. That is not the case anymore. I let go of it and I think, well we will see if the moment is there. And of course I already made it until here. I still want to do a lot of things. I want to continue, I want to continue life, to enjoy my children, my husband, and my acquaintances.*

Patients who refused treatment, on the other hand, focused more on their end of life rather than on how to stay alive and how to define life choices. Some patients refused treatment and expected to die because they had not accepted life-prolonging treatment. Other patients, however, refused treatment because they expected to die if they would accept the recommended treatment; they thought the treatments were death-hastening with a lot of suffering. The interviews showed that experience with death and dying of relatives or close friends, especially experience of suffering and pain, influenced patients' decisions on their own end of life. Patients who refused treatment associated these experiences with treatment decisions: they did not want to die 'while shopping from one to another medical treatment'.

Patient 16 (Rc): ... *"an acceptable investment in life-prolonging". Well, I don't think so. No, because if it would turn out badly, then I don't want in any case feel continuously ill for the remaining years or have pain somewhere because of treatment, or the consequences of treatment. (...) No, I don't think that is acceptable. I then prefer to die one or two years earlier, but still feeling reasonable.*

Patient 13 (Rnc): *As such for me it is a very clear consideration: if I could not really be cured, and it [treatment] is only life-prolonging – and in what way – what kind of a life would I have then, how would I feel, and what would I be able to do?*

Patient 24 (Rnc): ... *I stated in advance that I only want to let these things be done that will not affect my quality of life. Thus, I absolutely don't want that – and chemotherapy would be part of this – for three months you've been miserable, to*

gain three months of life. Then I would lose in my good time and gain in my bad time.

Table 2 Frequencies in end-of-life attitudes of patients who refused curative treatment (Rc, $n_{pat}=10$), who refused non-curative treatment (Rnc, $n_{pat}=20$), who accepted curative treatment (Ac, $n_{pat}=7$), and who accepted non-curative treatment (Anc, $n_{pat}=15$). Rt = total refusal-group ($n_{pat}=30$); At = total acceptance-group ($n_{pat}=22$). χ^2 is given comparing Rt and At.

	Total	Rc	Rnc	Rt	(%Rt)	Ac	Anc	At	(%At)	χ^2 , p (df=1)
Fighting death	13	2	2	4	(13)	2	7	9	(41)	5,147*
Avoiding death	19	3	5	8	(27)	6	5	11	(50)	2,980 [#]
Fearing death	9	1	4	5	(17)	1	3	4	(18)	0,020 ^{ns}
Fearing dying	8	1	3	4	(13)	1	3	4	(18)	0,229 ^{ns}
Making (funeral) arrangements	8	2	3	5	(17)	0	3	3	(14)	0,090 ^{ns}
Controlling death	17	4	6	10	(33)	2	5	7	(32)	0,013 ^{ns}
Accepting death	21	6	10	16	(53)	2	3	5	(23)	4,938*

* $p < 0,05$; # $p < 0,10$

3.3.4 End-of-life attitudes and demographic characteristics

In Table 3, demographic characteristics of patients categorized as 'fighting death', 'accepting death' and 'avoiding death' are given. The focus is on 'fighting death' and 'accepting death' because for these two end-of-life attitudes significant differences could be observed between accepting and refusing treatment (see Table 2). In addition, the focus is on 'avoiding death', because for this end-of-life attitude a trend could be observed between accepting and refusing treatment.

No significant differences in mean age of the patients between the different end-of-life attitudes could be determined. Significant differences could be observed for the end-of-life attitude fighting death: (1) between married patients and single, divorced or widowed patients, and (2) between patients without children and patients with independent or dependent children.

Table 3 Demographic characteristics of patients categorized as ‘fighting death’ ($n_{ela}=13$), ‘accepting death’ ($n_{ela}=21$), and ‘avoiding death’ ($n_{ela}=19$)

	fighting death	accepting death	avoiding death
<i>Mean age</i>	54 (sd=8,04)	58,67 (sd=15,08)	56,05 (sd=15,24)
<i>Gender</i>			
Male ($n_{pat}=22$)	23%	32%	27%
Female ($n_{pat}=30$)	27%	47%	43%
<i>Marital status</i>			
Single/divorced, widowed ($n_{pat}=16$)	0%	56%	38%
Married/registered partnership ($n_{pat}=36$)	36% ^{*1}	33%	36%
<i>Children</i>			
No ($n_{pat}=10$)	0%	40%	40%
Yes (independent) ($n_{pat}=26$)	27%	46%	31%
Yes (dependent) ($n_{pat}=16$)	38% ^{*2}	31%	44%
<i>Education</i>			
Primary school/lower level high school ($n_{pat}=15$)	40%	40%	47%
Middle level high school ($n_{pat}=13$)	15%	54%	46%
Advanced vocational/university ($n_{pat}=24$)	21%	33%	25%

*1 ($\chi^2=7,704$ (df=1), $p<0,05$); *2 ($\chi^2=4,718$ (df=2), $p<0,05$)

3.3.5 End-of-life attitudes and euthanasia

Euthanasia was mentioned by patients in all of the four treatment groups (categorized as ‘controlling death’, Table 2). Demographic characteristics of the patients categorized as ‘controlling death’ are given in Table 4. No significant differences could be observed.

The interviews showed that patients desired euthanasia because they wanted to stay in control and did not want to be dependent on physicians during a treatment process. Patients wanted to take their fate into their own hands and responsibility for their last phase of life. They preferred not ‘to get old, ill, and demented’, rather they wanted to choose their own moment and way of death.

Table 4 Demographic characteristics of patients categorized as 'controlling death' ($n_{ela}=17$)

	controlling death
<i>Mean age</i>	55,35 (sd=11,77)
<i>Gender</i>	
Male ($n_{pat}=22$)	36%
Female ($n_{pat}=30$)	30%
<i>Marital status</i>	
Single/divorced, widowed ($n_{pat}=16$)	31%
Married/registered partnership ($n_{pat}=36$)	33%
<i>Children</i>	
No ($n_{pat}=10$)	40%
Yes (independent) ($n_{pat}=26$)	35%
Yes (dependent) ($n_{pat}=16$)	25%
<i>Education</i>	
Primary school/lower level high school ($n_{pat}=15$)	20%
Middle level high school ($n_{pat}=13$)	23%
Advanced vocational/university ($n_{pat}=24$)	46%

We compared patients' desires for euthanasia with the other end-of-life attitudes (Table 5).

Table 5 Frequencies in desire for euthanasia ($n_{pat}=17$) or not ($n_{pat}=35$) related to end-of-life attitudes

	total	desire for euthanasia <i>n</i> (%)	no desire for euthanasia <i>n</i> (%)	χ^2 , <i>p</i> (df=1)
Fighting death	13	3 (18)	10 (29)	0,728 ^{ns}
Avoiding death	19	3 (18)	16 (46)	3,887 [*]
Fearing death	9	2 (12)	7 (20)	0,542 ^{ns}
Fearing dying	8	6 (35)	2 (6)	7,691 ^{**}
Making (funeral) arrangements	8	5 (29)	3 (9)	3,818 [#]
Accepting death	21	9 (53)	12 (34)	1,654 ^{ns}

** $p < 0,01$; * $p < 0,05$; # $p < 0,10$

The results revealed that 35% of the patients who desired euthanasia feared dying, 18% avoided death, and 29% had made (funeral) arrangements compared to respectively 6%, 46%, and 9% of the patients who did not desire euthanasia. No significant differences could be observed for the end-of-life attitudes 'fighting death', 'fearing death', and 'accepting death'.

3.4 Discussion and conclusion

The objective of this study has been to evaluate patients' attitudes regarding death and dying in relation to decisions to refuse or accept recommended oncological treatment. We used a qualitative approach to investigate which motives underlie patients' decisions. Seven end-of-life attitudes were distinguished: fighting death, avoiding death, fearing death, fearing dying, making (funeral) arrangements, controlling death, and accepting death. These seven end-of-life attitudes appeared to be in line with attitudes described by several quantitative instruments that measure death attitude: the Death Attitude Profile-Revised¹⁵, the Multidimensional Fear of Death Scale¹⁶, and the Coping with Death Scale¹⁷. In addition, 'controlling death' is a known terminology in the context of the euthanasia debate^{18,19} and terminologies such as 'fight against the tumour'²⁰, 'fighting cancer'²¹, 'fight for life'²², and 'fighting death'²³ are used to describe patients who fight against death or physicians who fight for their patients. Thus, the end-of-life attitudes distinguished in our study are confirmed by literature, but they have never been qualitatively categorized or put together for cancer patients who decide on oncological treatments. As our results show, a qualitative approach can give a rich understanding of patients' attitudes and strengthens the interpretation made about them: considerations and deliberations of patients related to treatment decision making come to the surface, end-of-life attitudes can more precisely be defined using quotations, and factors related to end-of-life attitudes can be distinguished.

From our study it can be concluded that end-of-life attitudes play a role in decision-making processes regarding accepting or refusing oncological treatment: a majority of the patients who had refused treatment also accepted death. They particularly focused on the end of their life. A majority of the patients who had accepted treatment fought against death or avoided death. They focused on how

to stay alive and how to define life choices. Differences in end-of life attitude could not be related to the age of the patients. Our study suggests that having a social network is an important factor in the decision-making process: first, being married or having a registered partnership and having dependent children were more frequently associated with accepting oncological treatment than with refusing treatment. As a matter of fact, the results show that it is important to distinguish between having dependent and having independent children: patients who refused treatment were more likely to have independent children, whereas patients who accepted treatment were more likely to have dependent children. Second, we found that only a few patients who were married or had a registered partnership refused curative treatment compared to single, divorced, or widowed patients. And third, being married and having children seemed to be related to the end-of-life attitude 'fighting death': patients were motivated in their fight against death by their social network. The fear of leaving behind their loved ones caused that most patients accepted treatment because they wanted to postpone death. A few patients who indicated to fight against death, on the contrary, did not accept treatment because they expected that accepting treatment would worsen their own condition and would hasten death. Interestingly, patients who fight against death seem to have different ways of fighting: for most patients fighting is related with accepting treatment, but for some with refusing treatment. The latter group of patients indicated to be afraid of the side effects and suffering caused by treatment; fear that could have been developed by earlier experiences of the patient him or herself, or by experiences seen with others. Although the interviews suggest that this fear is part of the end-of-life attitude 'fearing dying', we found no strong relationship between fear of dying and accepting or refusing a treatment. The results suggest, however, that fear of dying, which according to our results includes fear of pain and suffering, is related to a desire for euthanasia. Many studies report that pain itself is not a major determinant of interest in or use of euthanasia or physician-assisted suicide²⁴⁻³⁰, whereas suffering is.²⁵ A distinction between pain and suffering made by Van der Wal et al.²⁵ could not be confirmed in our study: patients indicated fear of pain as part of their fear of suffering. We stipulate a difference between *fear* of pain and suffering and *actual ratings* of pain and suffering. In our opinion, good (palliative) care can offer relieve of pain and

suffering using medical techniques, leading to patients feeling physically comfortable. However, decreasing fear of pain and suffering asks for more than a medical technical solution; this needs an exploration of patients' ideas about the last part of their lives and of the information the patient has received about the possibilities to relieve pain and suffering.

It should be noted that we did not investigate actual requests for euthanasia, but early desires for euthanasia. Patients deliberately discussed their treatment decision and reported to have a future desire for euthanasia, although they were not yet in a terminal stage of their disease. The study suggests that patients desire euthanasia because they want to stay in control and do not want to be dependent on physicians. In the Quill-case, as described in the introduction, the patient's wish to stay in control seemed to be reflected in both the decision to refuse oncological treatment and in the patient's wish for hastened death. We, however, did not observe a relationship between treatment refusal or acceptance and a desire for euthanasia: both, in the group of patients who refused and who accepted treatment there was a comparable percentage of patients who desired euthanasia.

From a survey in England, Seale et al. concluded that besides having cancer, being of higher social class and not being mentally confused are independently predictive of full open awareness of dying. Additionally, these individuals are more likely to have spoken of their desires for euthanasia.¹⁸ We could not observe a strong relationship between educational levels and end-of-life attitudes, although for patients who desired euthanasia, the percentage of patients with high educational levels was around twice as high as for patients with middle or low educational levels. With regard to the mental state of patients as mentioned by Seale, measures of depression and psychological distress could be interesting in follow-up research on end-of-life attitudes. Previous studies investigating the associations between the desire for death and major depression have indicated the existence of an association.^{26,29,31,32} A study of Akechi et al., however, did not reveal an independent association between major depression and suicidal ideation. They argued that psychological distress, rather than a clinical diagnosis of major depression, is a more important indicator.³³

In addition to measuring depression and psychological distress, it would be interesting to investigate how end-of-life attitudes change over time. Our study

describes end-of-life attitudes of patients at just one moment in their disease process. But since among dying patients the will to live shows substantial fluctuations,^{34,35} death attitudes may change over time, especially when patients suffer from a progressive terminal disease.^{26,28} Goodall described how three of her good friends died and how she saw their attitudes change: denial changed into restlessness, suicidal thought changed into an acceptance of palliative medication, and depression lifted.²³ These descriptions suggest a chronological and presumably mutually exclusive progression of end-of-life attitudes in relationship to one another. In addition, Jones et al. found that a desire for hastened death in cancer patients was incrementally related to the stage of disease.³² It would be interesting to investigate whether there indeed exists a chronological relationship between progression of disease and end-of-life attitudes of patients who decide on oncological treatment or whether a relationship that allows a more fluid progression or waxing and waning of attitudes could be more in tune than a chronological one.

Our study stresses the importance of discussing patient norms and values, including end-of-life attitudes, not only in the terminal stage of a patient's disease, but already in earlier stages of the disease and treatment process. In all these stages patients make important treatment decisions that may be influenced by their ideas on the end of life. In medical practice, the generally accepted model underlying treatment decision making begins with a set of clinical circumstances and choices. The perception of chances of improvement and sometimes also the underlying values then would inform attitudes that guide ultimate decision making. We suggest that more reflective attention is needed for the end-of-life attitudes of patients. Physicians' attention for philosophical questions about the end of life may help to understand a patient's treatment decision, including refusal of oncological treatment.

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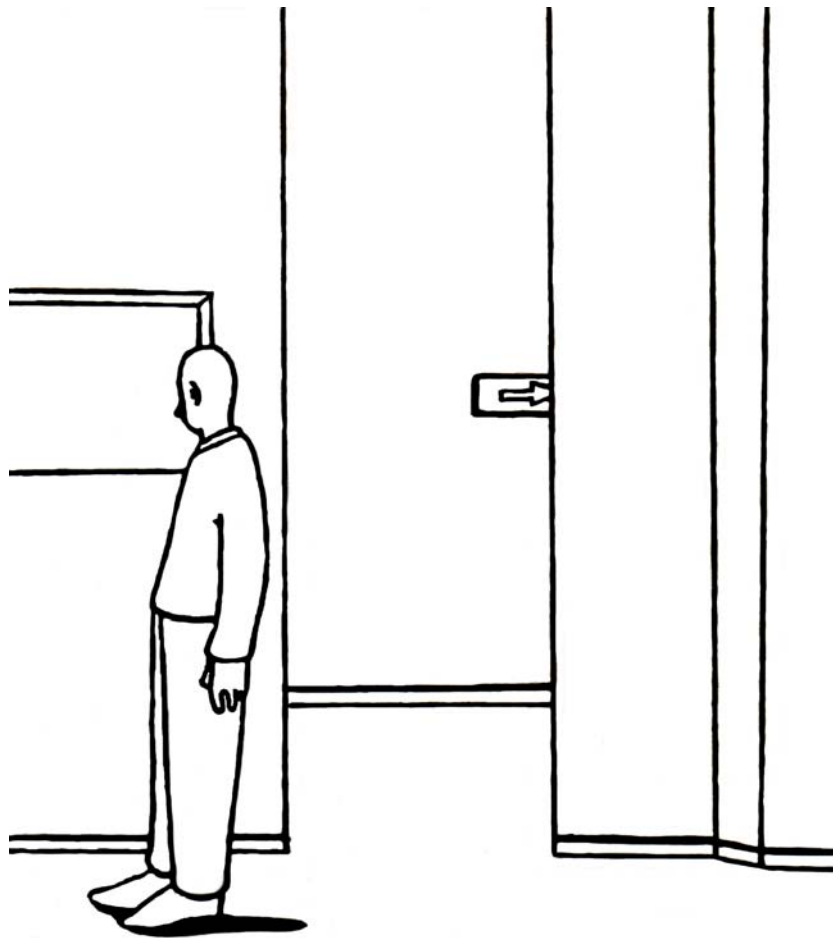
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Chapter 4

The medical practice of patient autonomy and cancer treatment refusals: a patients' and physicians' perspective



Van Kleffens T, Van Baarsen B, Van Leeuwen E. The medical practice of patient autonomy and cancer treatment refusals: a patients' and physicians' perspective. *Social Science & Medicine* 2004; 58:2325-2336.

4 The medical practice of patient autonomy and cancer treatment refusals: a patients' and physicians' perspective

The idea that patients should take up an autonomous position in the decision-making process is generally appreciated. However, what patient autonomy means in the case of patients who refuse a recommended oncological treatment has not been investigated. This study aims to clarify how the concept of patient autonomy can be applied to patients who refuse a recommended oncological treatment. Focus questions are: (1) what is meant by patient autonomy, i.e. how is this autonomy conceptualized and (2) which factors influence patient autonomy. A qualitative study design with in-depth interviews was performed. The study sample included 30 cancer patients and 16 physicians. All patients had refused a recommended oncological treatment.

Patient autonomy was revealed to be a comprehensive concept with elaborations on 'making decisions' and 'defining life choices' as sub-concepts of patient autonomy. In contrast to what is generally believed, decisions of patients to refuse an oncological treatment do not so much rely on the medical information about disease and treatment options, but are rather inspired by patients' own experiences or those of close others. The medical information and the role of the physician do, however, influence patients' experiences of being free and/or of having a choice. The results show that the extent of pressure physicians will exert to persuade the patient to be treated as recommended depends on the medical distinction between a curative and a non-curative treatment goal. It seems that there exists a shift in respecting patient autonomy, which depends on factors like treatment goal. Discussing the respect shift may serve to clarify underlying thoughts and principles in the decision-making process for both physicians and patients.

4.1 Introduction

Decision making about adequate cancer treatment has long been an asymmetrical process. The physician used his or her skills and knowledge to choose the best optional treatments for his or her patient. During the last two decades, it has become usual that patients play a more active and autonomous role. Concepts like patient autonomy and informed consent have been used to balance physicians' dominance in medical decision making.

4.1.1 Patient autonomy

Nowadays, patient autonomy is of fundamental importance in health care and medical ethics. Autonomy is considered to be one of the leading principles of medical ethics. At the same time, conceptual confusion and uncertainty continues to surround the actual concept of autonomy.¹ In medical ethics, different meanings have been attached to the concept. Some theories have featured autonomous

choice with dominance on self-determination,^{2,3} while others have questioned this conception of autonomy and have stressed a more relational conception.⁴⁻⁷ According to Feinberg, autonomy can be used to refer to a capacity, an actual condition, a character ideal, and a right to sovereign authority.^{8,9} In addition, theories about patient autonomy referring to authenticity¹⁰ or identity¹¹ have been developed. As Schermer has described: “autonomy is best understood as an umbrella notion that can cover different aspects”.¹

4.1.2 Informed consent

Central to the interpretation of patient autonomy in clinical practice is the notion of informed consent. Informed consent can be defined as the autonomous authorisation of a medical intervention by a patient.¹ According to Faden and Beauchamp, this authorisation is autonomous if it is given intentionally, with understanding, and without controlling influences.¹² The medical information patients receive, is thought to determine patient autonomy in the decision-making process. The disclosure of information has even been assumed to be necessary for autonomous decision making.^{2,13}

Laws have been introduced to ensure greater patient control and to reduce dominance of physicians, such as the Patient Self-Determination Act in the USA (enacted in 1991) or the Dutch Self-Determination Act (WGBO) in 1995.¹⁴ According to the latter act, the physician has to inform the patient before a treatment is started. After being informed by a medical expert, the patient can make a well-informed and deliberate treatment decision.^{14,15} If a physician treats a patient without having informed consent, this can, according to the Dutch Civil Code, be designated as wrongful act for which the physician is liable.

The relationship between the disclosure of medical information and the decision made by the patient has been the subject of many studies.¹⁶⁻²⁰ From these studies it appears that patients' preferences for medical information do not automatically imply an autonomous role in the decision-making process.^{16-18,20} Followfield even argues that when discussing treatment options, a clear distinction needs to be made between patients' preferences for information and their desire for participation in decision making.²⁰

4.1.3 Treatment refusals

The medical information patients receive often contains a treatment recommendation, reflecting the best medical option for the patient. However, patients do not only include medical information and medical deliberations in their decision-making process. Their deliberations regarding treatment decisions may consist of different factors: “A mixture of feelings, personal circumstances, goals, beliefs, thoughts, and calculations” guide the patient in this process.²¹ Therefore, although the majority of the patients readily accepts the recommended treatment, some patients do not arrive at the treatment as recommended by the physician. The patient’s deliberations may sometimes result in (partial) refusal of (further) treatment.

The physician-patient relationship in medical decision making has frequently been studied and discussed.²²⁻²⁸ Treatment refusals and their moral applications have often been discussed concerning issues such as Do Not Resuscitate (DNR) orders,²⁹ withdrawal of life-sustaining treatment (for example, ventilation),³⁰ blood transfusions for Jehovah’s Witnesses,³¹ and coercion in psychiatry.³²⁻³⁴ These discussions are often made from the perspective of patient autonomy as conflicting with the responsibilities of clinicians. Patient autonomy is also the central value cited in defence of honouring refusals based on religious values.³¹ In psychiatry, patient autonomy is also much emphasized to refer to conflicts between patients having a right to refuse treatment (as long as the patient does not harm others) and physicians being paternalistic in coercing patients.³²⁻³⁴ To our knowledge, an exploration of the various moral deliberations of patients and physicians during the decision-making process concerning treatment acceptance and refusal in oncology has, however, not yet been performed.

4.1.4 The study

It has always been endorsed that physicians should be acquainted with the patient’s deliberations and that the physician understands the patient’s motives. According to the American Society of Clinical Oncology, modern cancer care should accordingly be responsive to the patient’s wishes and be consistent with

his or her values.³⁵ But what are those values? And what does it mean for the physician to be responsive to the patient's wishes when the patient refuses a recommended treatment with a curative goal? How does this relate to the concept of patient autonomy? In other words: what is the practical implication of patient autonomy when a patient refuses a recommended oncological treatment? This study aims to clarify these questions. By using data from interviews with patients and physicians, we focus on two aspects: firstly, we discuss what is meant by patient autonomy and how this autonomy is conceptualized, and secondly, we elaborate on factors that influence patient autonomy.

4.2 Methods

The present study is based on in-depth interviews with patients and physicians. All patients had refused a recommended oncological treatment. In this study, refusal means that the patient did not start treatment at all, stopped during treatment, or refused a part of a recommended treatment but accepted another part (for example, accepted surgery, but refused chemotherapy). A qualitative research method has been chosen to explore patients' deliberations that led to refusal of a recommended oncological treatment and to determine physicians' attitudes to treatment refusals. Our study was approved by the Medical Ethics Committees of the study sites. All patients gave informed consent.

4.2.1 Participants

We used a broad definition of refusal, since patients who refuse an oncological treatment are difficult to include in a research sample.²¹ One reason may be that after their refusal, they withdraw from the medical circuit and are therefore difficult to approach. Another reason may be that patients, after their withdrawal, do not want to be involved in medical research anymore, either because they do not want to be confronted again with hospitals or doctors, or because they are too ill to be interviewed. The patients included in this study form a rather unique sample and deserve our gratitude.

The patients were asked to participate by general practitioners ($n=5$), and by specialists in a university hospital ($n=6$) and in five general hospitals ($n=2$) in the Netherlands. Dutch associations for cancer patients were willing to spread information about the study. Seventeen patients participating in associations announced themselves for participation. The fact that a number of patients were obtained from associations for cancer patients may suggest that the patients in the study are not representative of the population of patients with cancer. However, most of the patients became acquainted with the associations only after they had refused the recommended oncological treatment. This indicates that patients' decision making was not influenced by their participation in patient associations.

Thirty patients were interviewed. Inclusion criteria were: being over the age of 18, speaking and understanding Dutch language, having cancer, having a life-expectancy of more than three months, and having refused a recommended oncological treatment. All patients announced by physicians or those who announced themselves from January 2001 until April 2002 were included in the study if they met the inclusion criteria. Since patients participating in associations announced themselves for participation, no medical files of these patients were available and therefore the stage of disease (TNM-classification) could not be retrieved. We included both patients who had refused recommended treatments with higher potential benefits (curative treatments) and patients who had refused recommended treatments with lower potential benefit (non-curative treatments). Patients who are facing a cancer diagnosis with curative opportunities may respond differently to their treatment recommendation than those with non-curative opportunities. Therefore, the patients were split up into four treatment groups (Table 1): (1) refused curative surgery, (2) refused another curative treatment, (3) refused non-curative chemotherapy, or (4) refused another non-curative treatment.

Demographic and clinical characteristics of the patients by treatment group are given in Table 2. The mean age of the patients ($n=30$) was 58 years (range 23-91), 60% of the sample was female, almost all patients (93%) were white Dutch, and 57% was married or had a registered partnership. Of the patients who had children (83%), 28% had dependent children, and a minority of the patients (37%) had grandchildren. Half of the patients had a high educational level (advanced vocational/university). The majority of the patients (64%) were patients with

mammary carcinoma or gastroenterological cancer (primary cancer of the intestine, stomach, oesophagus, or liver).

Table 1 Patients who had refused a recommended oncological treatment were split up into four treatment groups

Group	Treatment	<i>n</i> (%)
1	Refused curative surgery (e.g. mammary carcinoma)	7 (23)
2	Refused curative other treatment (e.g. non-Hodgkin lymphoma)	3 (10)
3	Refused non-curative chemotherapy (e.g. colon carcinoma)	14 (47)
4	Refused non-curative other treatment (e.g. prostate carcinoma)	6 (20)

Due to small numbers in the cells, representing the demographic and clinical characteristics of the patients by treatment group, no χ^2 tests could be performed to test for differences between the different treatment groups. We could, however, observe some trends when we compared patients who refused a curative treatment (treatment groups 1 and 2) with patients who refused a non-curative treatment (treatment groups 3 and 4): firstly, more patients refused a non-curative treatment than a curative treatment. Secondly, half of the women refused a curative treatment, whereas of the men, only one refused a curative treatment. And thirdly, a minority of the patients who were married or had a registered partnership refused a curative treatment, whereas half of the single, divorced, or widowed patients refused a curative treatment.

Sixteen physicians were interviewed. We made a selection of eight general practitioners and eight (general) oncologists out of all the physicians who participated in the study ($n=78$). To obtain a wide range of different opinions, we included younger and older physicians, males and females, physicians with few and many years of working experience, and physicians from different settings (university hospital and general hospital). Physician characteristics are given in Table 3. The mean age of the physicians was 49 years (range 29-60), 31% of the sample was female, and the mean number of years of working experience was 18 years (range 2-29). The interviews were held from May 2002 until October 2002.

Table 2 Demographic and clinical characteristics of patients ($n=30$) split up into four treatment groups: (1) refused curative surgery, (2) refused another curative treatment, (3) refused non-curative chemotherapy, or (4) refused another non-curative treatment

	<i>M (range)</i>	Treatment group				<i>n (%)</i>
		1	2	3	4	
<i>Age</i>	58 (23-91)					
<i>Gender</i>						
Male		1	0	9	2	12 (40)
Female		6	3	5	4	18 (60)
<i>Race</i>						
White Dutch		6	3	13	6	28 (93)
White other		1	0	1	0	2 (7)
<i>Marital status</i>						
Single/divorced, widowed		5	2	5	1	13 (43)
Married/registered partnership		2	1	9	5	17 (57)
<i>Children</i>						
No		2	0	3	0	5 (17)
Yes (not at home)		4	2	8	4	18 (60)
Yes (at home)		1	1	3	2	7 (23)
<i>Grandchildren</i>						
No		5	2	7	5	19 (63)
Yes		2	1	7	1	11 (37)
<i>Education</i>						
Primary school/lower level high school		4	1	3	1	9 (30)
Middle level high school		1	1	3	1	6 (20)
Advanced vocational/university		2	1	8	4	15 (50)
<i>Cancer diagnosis</i>						
Breast		4	2	2	3	11 (37)
Gastroenterological		1	0	5	2	8 (27)
Urological		1	0	1	1	3 (10)
Gynaecological		0	0	2	0	2 (7)
Pulmonary		0	0	2	0	2 (7)
Haematological		0	1	1	0	2 (7)
Other		1	0	1	0	2 (7)

4.2.2 Interview procedure

The patient interviews were carried out at the patient's home. Each interview lasted between 60 and 120 min. We used in-depth interviews. This means that the interviews contained some general topics and no close-ended questions.³⁶ The interview topics concerned demographic and clinical characteristics of the patient, the course of the disease, communication with physicians about the recommended

treatment, the attitudes of the patient to the recommended treatment, and future perspectives of the patient. The interview topics were formulated after studies of relevant literature and observations. During the observational studies, 72 patients were observed during their visit to five different oncologists at an oncological outpatient clinic in the Netherlands. From these transcripts, aspects that came up for discussion between physician and patient and deliberations of patients with regard to recommendations for treatment were derived and converted into interview topics.

The physician interviews were carried out in the physician's office. Each interview lasted between 30 and 60 min. The in-depth interview topics concerned characteristics of the physician, working experience, curative versus non-curative treatments, and palliative care in oncology, physician-patient relationship especially concerning treatment decisions, treatment refusals, patient autonomy, and physician's beneficence. The interview topics were formulated after literature studies and after raw analysis of the patient interviews.

Table 3 Characteristics of physicians ($n=16$)

	<i>M (range)</i>	<i>n (%)</i>
<i>Age</i>	49 (29-60)	
<i>Gender</i>		
Male		11 (69)
Female		5 (31)
<i>Profession</i>		
General practitioner		8 (50)
(General) oncologist		8 (50)
<i>Work experience</i>	18 (2-29)	

4.2.3 Analysis

All the patient and physician interviews were audio-taped and transcribed. Grounded theory methods were used to analyse the interviews. Grounded theory is a general methodology for developing theory based on systematically gathered and analysed data.³⁷ Grounded theory is considered to be the best available method for analysing data when the subject in question is a process and the

research questions concern an experience.³⁸ During the analysis, we used computer software based on grounded theory (Kwalitan 5.0) for multiple text management, including coding, locating, and retrieving key materials, phrases, and words. After retrieving key materials (quotations), we analysed the quotations on whether these could be traced back to patients in one particular treatment group (Table 1). No distinction between the four groups could be observed. So, for simplicity and clarity, we performed analyses for two groups: patients who refused a curative treatment (treatment groups 1 and 2) and patients who refused a non-curative treatment (treatment groups 3 and 4). In cases where there appeared to exist any difference between these two groups, it is described in the results.

4.3 Results

4.3.1 Patient autonomy

To be able to discuss patient autonomy in the decision-making process of patients who refuse an oncological treatment, it is necessary to explore what is meant by patient autonomy and how this autonomy is conceptualized. In our study, we did not focus on patient autonomy as a theoretical concept. Instead, we approached the concept from the practical point of view based on conceptions of physicians and patients in the actual practice of medicine.

Physicians

Physicians indicated that one could conceptualize patient autonomy in two ways. First, patient autonomy defined as a patient who makes decisions. In the second conceptualisation, patient autonomy is defined as a patient who defines life choices. These two conceptualisations were mentioned either as different or as integrated concepts.

Physician 1: ... *that you are able to make a choice for yourself, give meaning to your own life, and make your own decisions.*

Physician 2: *Well, in the end it is the patient who is empowered to make the decision, and can do so as well.*

Patients

In the patient interviews, patient autonomy is also represented as 'making decisions' and 'defining life choices'. However, the patient interviews show that these representations of patient autonomy as 'making decisions' and 'defining life choices' can be further elaborated. In the decision-making process, some patients indicated that it was of crucial importance that the decision they made concerned their *own* life and their *own* body. Patients indicated that only they could make the treatment decision, wanted to make that decision, and thought that they had to make that decision.

Patient 1: *You do have to make a choice, because it's your decision, and it's about your body.*

Patient 2: *I think I didn't care at all what he [husband] thought about it [decision] at the time. It may seem very strange, but it's my life that's at stake.*

Another elaboration was the possibility of patients to choose between options, for example, the option of no treatment at all or the option of no life-prolonging treatment.

Patient 3: *I'm old enough to say, 'Well, okay, I even have three choices.' I can also choose to say, 'I don't have to do anything and I'm going back home.'*

Patient 4: *We have to make that choice ourselves. Do I really want to face a few miserable months or do I want a few months in which I may feel pain, but not so many more problems? You have to be able to make that choice.*

Besides choosing for a particular option, some patients found it really important to take personal initiatives during their disease, for instance to find their way in alternative medicine. Taking personal initiatives was sometimes more appreciated than being treated in a passive way, or doing nothing at all.

Patient 5: *I knew a Moerman-physician [physician in alternative medicine, TvK]. I visited him. (...) I also bought the Houtsmuller-book [book about food health and natural food, TvK]. So I could take the initiative again. I think it's very important to be able to do something, not just taking your pills or waiting for your injection in the morning, but to do something yourself.*

Interestingly, the concept of autonomy appeared not only to be represented as elaborations on 'making decisions' and 'defining life choices'. Four values revealed

to have a major significance in the process of patients' decision making: freedom, independence, trust, and responsibility.

(a) *Freedom*. Some patients, especially those who had refused a curative treatment, mentioned that having the freedom to choose a direction they preferred, was of great importance in their decision-making process.

Patient 6: ... *that you could choose, were free to choose, to go in a different direction.*

Patient 2: *I really felt very free with him [physician]. Yes, he explained all the options and I was able to choose by myself.*

(b) *Independence*. During their disease, some patients did not want to submit to the doctor since they wanted to be independent and wanted to have control about what was going to happen.

Patient 7: *A nasty feeling, submitting like that. Like I was putting my fate in the doctor's hands and he knows what's best for me and I just do everything he says. (...) Dependence, being nothing at all, yes, it's keeping control.*

(c) *Trust*. Not trusting the doctor and/or the medical establishment was sometimes given as an important reason for patients who indicated that they wanted to make their own decisions.

Patient 8: *I had gone through such a hard time with the conventional physicians over there, that I actually lost all faith in them.*

(d) *Responsibility*. By refusing a treatment, some patients felt that they themselves took responsibility for their own life. They felt that if they had accepted the recommended treatment, they had given the doctor responsibility.

Patient 2: ... *and always be the one who thinks that you are largely responsible for what you do. So, making choices, getting advice, I'm the one to decide about my own life.*

Patient 4: *My GP says, 'Nobody has taken responsibility for his own health like you have.' (...) In any event, I don't think, they have to make me healthy.*

4.3.2 Factors that influence patient autonomy

After the exploration of what is meant by patient autonomy and how patient autonomy is conceptualized, we have studied factors that influence patient autonomy in the case of patients who refuse an oncological treatment.

Physicians

According to the physicians, patient autonomy has a wide range. Although patients can often be autonomous, patient autonomy also has its limits. In other words: patient autonomy can never be absolute and is pliant.

Physician 3: *It [autonomy] is there, but pliant. There's a lot of it [autonomy], but not 100%.*

Physician 4: *The autonomy goes a long way, but [is] not complete.*

From the physician interviews it turned out that five factors influenced patient autonomy. Two factors were most mentioned:

(a) Physicians declared that the medical information about disease and about treatment possibilities is of fundamental importance for patient autonomy. A patient can only be autonomous when he or she has information that helps to grasp the subject about which the patient has to decide.

Physician 5: *If you say, 'On what does it [autonomy] depend?' Of course it depends on the patient's grasp of the subject: information about his illness, information about the treatment.*

Physician 6: *Autonomy without information is nothing, so it depends an awful lot on what kind of information the patient receives, how he receives it, what kind of decisions he makes.*

Physician 4: *How autonomous can a patient be? When all is said and done, it depends on the information you receive.*

(b) Physicians indicated that they themselves played an important role in the patient's decision-making process.

Physician 3: *You wonder what it is that patients base their decisions on. On some hope of getting better or on a doctor who says, 'I would do that if I were you' or something like that. Or that you're communicating it though not in so many words.*

Physician 7: *Because I know I can direct it and of course I try to do so as little as possible, but I still have some influence, at least I think I do.*

The influence of the physician appeared to be closely related to the goal of the recommended treatment. If the treatment goal is curative and the patient refuses treatment, physicians indicated that they are willing to exert more pressure to persuade the patient to be treated. If the treatment goal is non-curative, physicians declared to exert less pressure and to be more willing to respect patient autonomy.

Physician 2: *Well, if patients could just really realize what they may be missing, with the treatment they could obtain, if they continue, if they at least know that. Then I could accept it [treatment refusal]. And I'm talking particularly about palliative treatment. As to a cure, I would always be willing to go a bit further and possibly involve some colleagues.*

Physician 8: *Concerning palliative care, you don't have to be insistent, because it's a matter of your obligation to explain it clearly, and then the patient together with his family decides. Concerning a cure, you have to exert pressure. Of course it depends on the chance of a cure.*

Other factors mentioned by physicians as influencing patient autonomy were:

(c) The role of relatives and friends in the patient's decision-making process. Some patients let themselves be treated because the family wants them to.

Physician 5: *The family often exerts more pressure than the physician. (...) Then not only information and experience play a role, but also just how someone lets himself be influenced by his family.*

Physician 9: *There are people who let themselves be treated only because the family wants them to.*

(d) The way patients manage the information they receive. Patients understand and use the medical information in very different ways in their decision-making process.

Physician 5: *It also depends to some extent on intelligence, on what you do with the information you get.*

(e) The disease perception and the experiences with treatment, received by patients themselves or close others. Patients may use these experiences as an argument to found their decision.

Physician 5: *Experience also plays a very important role. Imagine, having had a friend who died just because he did or did not receive the same treatment.*

Patients

From the patient interviews it turned out that three factors were important in influencing patient autonomy:

(a) Patients' experiences and knowledge of the experiences of close others with cancer and cancer treatments. Most patients referred to their own experiences or experiences of others as a source of knowledge of what they could expect from being treated or not. These experiences seemed to have highly inspired patients' decision making.

Patient 6: *My mother who has been living with cancer for the past 25 years, unbelievable perhaps, has also refused any chemo and radiation therapy. But every few years a tumour has to be removed again, and she even still does her own housekeeping, she's 83. That is an example for me (...) in any event that you can live for so many years, that it doesn't mean you will die right away.*

Patient 8: *Besides, two days before I went to my GP, I had buried my friend who had been ill for six years. She had undergone all the standard things and suffered horribly. She was groaning with pain when I visited her at the hospital and I found it just terrible. (...) Afterwards I buried another friend who was also ill for six years. (...) I saw these friends of mine. I saw them suffering. (...) And since I have witnessed and seen all of that, I think well then perhaps just let me go, but don't torture me.*

(b) The influence of relatives, friends, or some professional in the decision-making process of the patient.

Patient 9: *So if it wasn't for my GP, I think I would have continued the treatment. The GP said, 'That's ridiculous. Take a holiday', he says. 'If you have the money, take a holiday, go to the beach and think about it.' That was really crucial, decisive.*

Patient 10: *Only that friend who put the idea into my head, I have to give him the honour of pushing me in that direction.*

Patient 11: *'I don't think it's such a good idea, what do you think? What do you think?' Well, he [another physician] says, 'I don't think it's such a good idea either.' Well, then I made my decision.*

Although some patients weighed the opinions of others against their own view, others did not. Most of the time, patients described the role of family and friends in

a way that suggests that family and friends leave the final decision to the patient while supporting every outcome of the decision, i.e. the treatment refusal.

Patient 12: *They [family] did see how I felt and I think that they also could see what another two courses of chemotherapy would do to me. They supported me, so that was okay.*

Patient 13: *I've talked with friends and with my family and they also say, 'It's your decision.'*

Although patients were not univocal in indicating whether or not others (physicians or relatives and friends) had influenced their decision-making process and the outcome of that process, the influence of the physician was, however, important to patients' experience of being free to make the decision to refuse a treatment; that is in not being forced to undergo treatment. Although most patients indicated that they experienced to be free in making their own decision, some patients did not have that experience. They felt that the decision took a lot of struggling, or they felt that an enormous amount of pressure was exerted on them to accept the recommended treatment.

Patient 14: *It took an awful lot of struggling (...), it's a fight with the outside world.*

Patient 15: *Of course Professor X exerted an enormous amount of pressure on me. (...) It was really too much pressure, especially to do the chemo.*

(c) As opposed to physicians, patients did not indicate the medical information they received about disease and treatment options as an important factor on which they relied in their decision to refuse a recommended treatment. Medical information did, however, have a serious effect on patients' experiences of having a choice. The possibility *not*-to-treat was only very rarely presented as an option. The absence of the possibility *not*-to-treat seemed to restrict the idea of having a choice. If there existed any choice, patients could choose between treatment options. In addition, most of the time, the recommended treatment was presented as the standard treatment for that particular disease. Patients, especially those who had refused a non-curative treatment, experienced offering a treatment as the standard treatment as a restriction of their possibility to choose.

Patient 9: *They [physicians] say, 'This is the standard thing, this is what we can offer you.'*

Patient 16: *That was it, that was standard. (...) But a patient with cancer is his own "hands-on" expert and physicians have to pay much more attention to what the patient himself experiences. They can learn a lot from their patients, like not saying, 'This is the European standard, these things make up the treatment and that's what you have to do.'*

In contrast to patients who had not experienced a choice, other patients found it self-evident that they had a choice, since they had made a decision about their own life or body. Some of these patients even indicated that they created their own choice since they had acquired their own information and knowledge.

Patient 17: *We [patient and husband] created a choice by ourselves by acquiring our own information.*

Patient 4: *We [patient and wife] didn't have any choice, no (...), but we made our own choices.*

4.4 Discussion and conclusion

It is generally acknowledged that treatment decision making is a difficult process for patients and physicians.^{22,24,39,40} Especially treatment refusals and their moral applications appear to be an interesting topic of discussion.²⁹⁻³⁴ Traditionally, physicians have been considered to rely almost exclusively on their own judgements about their patients' needs for treatment, information, and consultation. Nowadays, medicine is increasingly confronted with assertions of the patient's right to make an independent judgement about his or her medical fate.² The idea that patients should take up an autonomous position in the decision-making process is appreciated. This study investigates patient autonomy in the case of patients who refuse a recommended oncological treatment.

4.4.1 Patient autonomy: a multi-layered modality

In our study, we approached the concept of patient autonomy from a practical point of view by using empirical data retrieved from interviews. In line with earlier studies,¹ our research findings emphasize that there exists no single conception of

patient autonomy. In the specific situation of patients who refuse an oncological treatment, patient autonomy reveals to be a multi-layered modality. This modality is related to 'making decisions' and the way patients 'define life choices'. 'Making decisions' and 'defining life choices' are represented in notions such as deciding about your own body, choosing between options, and taking personal initiatives. Furthermore, the values of freedom, independence, trust, and responsibility reveal to have a major significance with regard to patient autonomy.

4.4.2 Medical information: being free or having a choice to make a decision

The relevance of medical information in decision making has increasingly been discussed in literature.¹⁶⁻²⁰ It is assumed that the disclosure of information is necessary for autonomous decision making.^{2,13} Accordingly, the physicians in our study have the opinion that patient autonomy highly depends on the medical information the patient receives about his or her disease and about the treatment possibilities. However, our study shows that patient autonomy is not only represented by informed patients who decide by weighing the pros and cons of medical information, like the informed consent procedure suggests. The results show that patients who refuse an oncological treatment do not so much rely on the medical information they receive about their disease or treatment options. Although patients need medical information to make decisions, this information is not an isolated instance. The content of the information is an important factor. Patient autonomy and the content of the medical information seem to be related to patients' experience of having the freedom to choose. A patient may not experience a possibility to choose whatever he or she prefers, if the possibility *not-to-treat* is not presented as an option and if the recommended treatment is presented as the standard treatment.

Over the last decades, studies about patient participation in decision making refer to choosing between treatment alternatives.²⁷ Our study shows that patient autonomy in its relation to freedom does not automatically imply the possibility to select among alternatives. An important distinction can be made between patients experiencing a choice and patients having the idea of being free to make a decision. A patient who does not experience a possibility to choose, can still have

the idea that he or she is free to refuse or accept a recommended treatment if the physician does not interfere in the decision-making process.

We argue that choosing between treatment alternatives is only one side of the picture that has been labelled with patient autonomy, namely that of freedom of choice. The other side of the picture is freedom without referring to choices, which applies to a patient's experience of being free in the decision-making process. This freedom may help the patient to make a decision that fits in his or her experiences and perspective of life. Thus, freedom and freedom of choice refer to the distinction between being free and having a choice respectively.⁴¹ Although the results indicate that there exists a difference between patients experiencing a choice and patients having the idea of being free to make a decision that is related to, respectively, patients who refused a non-curative treatment and patients who refused a curative treatment, we argue that this relationship cannot be proved. Being free to make a decision cannot be attributed to patients who refuse particular a curative or a non-curative treatment since both groups indicated that the physician influenced their experience of being free to make the decision to refuse a treatment.

4.4.3 Experiences: an important factor influencing patient autonomy

Patients who refuse an oncological treatment are particularly influenced by their former experiences or by what they have seen in the disease process of others having cancer or being treated for cancer. In line with Huijer and Van Leeuwen,²¹ we argue that to view a refusal as an autonomous choice, in which patients are informed about the pros and cons of treatment and have to decide by weighing them, seems not to be sufficient. Huijer and Van Leeuwen discussed that the refusals could be better comprehended in the framework of the patients' broader worldview: personal values, emotions, beliefs and attitudes towards life, suffering, and death have been mentioned in this context.

In line with Silverman et al.,⁴² we propose that in order to be able to determine how the patient perceives the medical information, it is important to check patients' ideas, convictions, and fears about cancer and being treated for it before giving further information about prognosis or treatment possibilities. As Tuckett et al.

observed in the 1980s, in only 6% of 1302 consultations the patient was asked about ideas and explanations about his or her own health status.⁴³ They referred to 'an ideal consultation' as a meeting between experts: that is, physicians are experts in disease and patients are experts in their own experiences of disease. According to Weston, a close engagement between physician and patient may not always be reached.⁴⁴ However, it is recognized that it is important that the physician and the patient find common ground. Therefore, it is important that physicians have certain skills that may help to create a situation in which they give the patient the medical information that fits in the patient's perspectives of life. The patient may only then effectively use the medical information in his or her treatment decision-making process.

4.4.4 Treatment goal: causing a respect shift

The medical distinction between a curative and a non-curative treatment goal strongly influences the extent of pressure physicians will exert to persuade the patient to be treated as recommended. Physicians may experience a distressful situation if their patient decides not to be treated with treatments which are generally considered beneficial or which are laid down in protocols as best practice. Even if the physician understands the patient in his or her decision, he or she may still experience a kind of inner conflict if the decision does not fit a medical rationale.⁴⁵ Physicians indicated to exert more pressure if patients refuse a curative oncological treatment, whereas, if the recommended treatment has a non-curative goal, physicians declared to exert less pressure and to be more willing to respect patient autonomy. Physicians' willingness to accept patients' treatment decision seems to be conditional. This conditionality is based on the proportionality of the decision, on the age of the patient, and, concerning non-curative treatments, on the extent of life-prolonging.⁴⁵ We argue that if the recommendations of the physician fit the patient's perspectives, as described above, the patient may be more inclined to accept the recommended treatment. Which, of course, does not imply that the physician has always to agree with the patient's ideas. A physician may disagree with the patients' ideas and may discuss these ideas and still respect patient autonomy if the physician at least understands the motives of the

patient. In our view, patient autonomy is not respected if the physician simply ignores the patient's motives.

It is noteworthy that in our study no cut-off point with regard to respecting patient autonomy was mentioned. Physicians did not use terminologies such as 'do respect' or 'do not respect' patient autonomy; not as a binary possibility of yes or no. Instead, physicians used sentences such as 'being *less* persuasive' or '*more* willing'. Thus, there seems to exist a shift in respecting patient autonomy. This respect shift resembles the psychological observable response shift. The response shift refers to a change in patient's perception of disease and depends on health changes.^{46,47} The respect shift refers to a change in the physician's attitude in respecting patient autonomy (or a change in the extent of exerted pressure) and depends on treatment goal. The respect shift may depend on other factors as well and is an interesting topic for future research. Discussing the respect shift may serve to clarify underlying thoughts and principles in the decision-making process for both physicians and patients.

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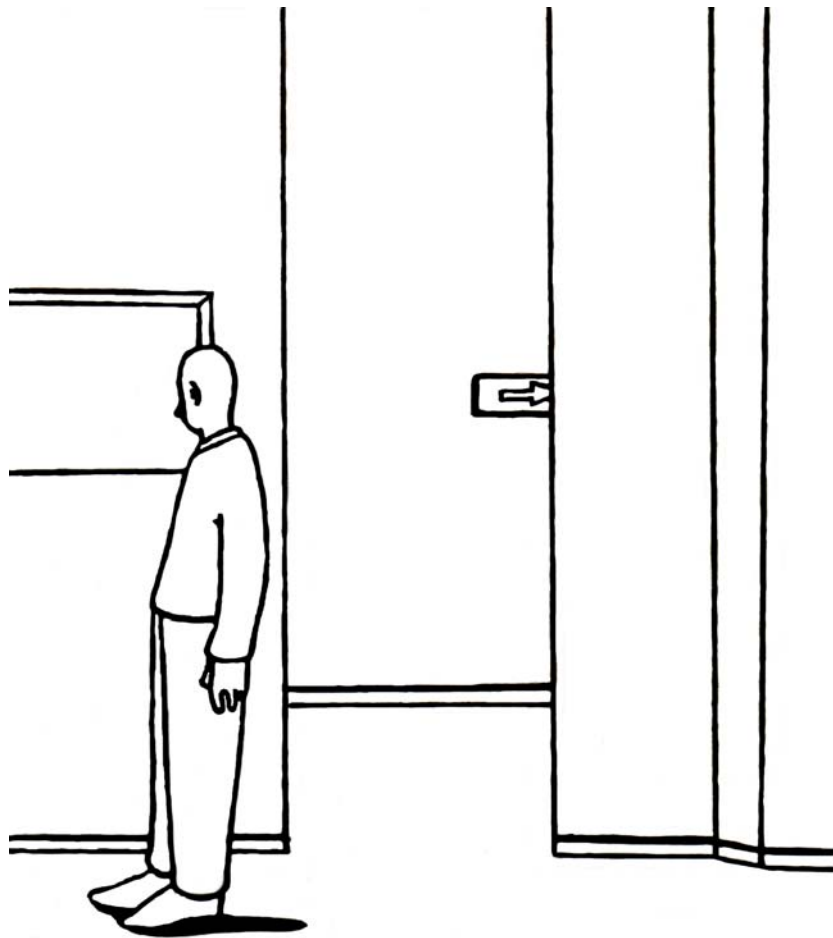
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Chapter 5

Patient autonomy in the context of cancer treatment refusal



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5 Patient autonomy in the context of cancer treatment refusal

We discuss how the results of our empirical study on cancer treatment refusal relate to the liberal understanding of patient autonomy, to the perspective of an ethic of care, and to the approach of patient-centered medicine. We focus on (1) patient autonomy as 'making decisions' and 'defining life choices', (2) the idea of freedom that is attached to patient autonomy, and (3) a patients' and a physicians' perspective in medical decision making.

In the context of cancer treatment refusal, patient autonomy can be understood as the opportunity to direct one's own decisions and to direct one's own life. Respect for patient autonomy therefore means both guaranteeing patients' choices ('freedom of choice'), and asks for respect for the way patients strive for their own individual goals in life ('freedom of being'). The liberal tradition has been criticized for not giving enough attention to a patients' perspective and for only paying attention to the patient's opportunity to choose. Respect for a patients' perspective is, however, included in the liberal understanding of patient autonomy, although indeed not so much emphasized. In addition, the liberal tradition is criticized for being too individualistic. Instead, an ethic of care and the approach of patient-centered medicine consider a more relational basis of patient autonomy. We show that in the context of cancer treatment refusal, the liberal understanding of patient autonomy and an ethic of care do not so much diverge as the critics suggest, at most a difference in emphasis exists. Combining the two perspectives may give optimal directions for a patient-physician relationship in which there is attention for choice between treatment alternatives, and for both the patient's and the medical perspective.

5.1 Introduction

Respect for patient autonomy has become an important moral principle in health care and is considered to be one of the leading principles in medical ethics. Still, much discussion is going on about the meaning and use of the concept of autonomy. Many authors have stressed the conceptual confusion and uncertainty that continues to surround the meaning of patient autonomy (for an overview, see Schermer¹). Different meanings have been attached to the concept: the liberal tradition has featured autonomous choice with dominance on self-determination^{2,3}, while an ethic of care has questioned this conception of autonomy and has stressed a more relational conception.⁴⁻¹⁰ In addition, in psychological literature, the approach of patient-centered medicine has stressed the issue of patient empowerment and has also discussed directions for interpreting patient autonomy.¹¹⁻¹⁴

Not only different theories, but different medical contexts as well cause different understandings of the concept of patient autonomy. In the context of treatment refusal, patient autonomy is often discussed concerning issues such as

Do Not Resuscitate (DNR) orders¹⁵, withdrawal of life-sustaining treatment¹⁶, blood transfusions for Jehovah's Witnesses^{17,18}, and coercion in psychiatry.¹⁹⁻²¹ To our knowledge, patient autonomy in the context of treatment refusal in clinical oncology has not yet been extensively discussed. We performed an empirical study to investigate what patient autonomy entails in the context of patients who refuse recommended oncological treatment. In our study, refusal means that the patient does not want to start oncological treatment at all, wants to stop during treatment, or refuses a part of a recommended treatment but accepts another part. In all of these cases, tension between physician and patient may appear due to disagreement on treatment policy. Consequently, questions are raised about the position of the patient and the role of the physician in the decision-making process, and thus about the meaning and use of the principle of respect for patient autonomy.

In this article, we discuss how the results of our empirical study relate to the liberal understanding of patient autonomy, to the perspective of an ethic of care, and to the approach of patient-centered medicine. Three topics deserve close attention: we focus on (1) patient autonomy as 'making decisions' and 'defining life choices', (2) the idea of freedom that is attached to patient autonomy, and (3) a patients' and a physicians' perspective in medical decision making.

5.2 Empirical study design

We have approached the concept of patient autonomy from a practical point of view by using empirical data retrieved from interviews with patients and physicians. A qualitative research method has been chosen to explore (1) patients' deliberations that led to refusal of recommended oncological treatment, (2) physicians' attitudes to treatment refusal, and (3) the position of patient and physician in the decision-making process.

A total of 30 patients (mean age 58 years, range 23-91) were interviewed. The inclusion criteria were: (a) age more than 18 years; (b) able to speak and understand Dutch; (c) having cancer; (d) life expectancy of more than three months; and (e) having refused a recommended oncological treatment. The patients were asked to participate by general practitioners ($n_{pat}=5$) and by

specialists in a university hospital ($n_{pat}=6$) or in general hospitals ($n_{pat}=2$) in the Netherlands. Dutch associations for patients with cancer were willing to spread information about the study. Patient members of these associations ($n_{pat}=17$) responded themselves to the call to participate. All patients recruited by the physicians or those who responded themselves between January 2001 and April 2002 were included in the study if they met the inclusion criteria. We included both patients who had refused a recommended treatment with higher potential benefit (curative treatment, $n_{pat}=10$) and patients who had refused a recommended treatment with lower potential benefit (non-curative treatment, $n_{pat}=20$). All patients gave written informed consent.

Each patient interview was carried out at the patient's home. Each interview lasted between 60 and 120 minutes. We used in-depth interview techniques. This means that the interviews contained some general topics and no close-ended questions.²² The interview topics covered demographic and clinical characteristics of the patient; the course of the disease; communication with physicians about the recommended treatment; the patient's attitude to the recommended treatment; and the patient's perspectives of the future. The interview topics were formulated after examining the relevant literature and undertaking preliminary observational studies.^{23,24} In these studies, 72 patients were observed during their visits to five different oncologists at an oncological outpatient clinic in the Netherlands. From the transcripts, various aspects of the discussion between physician and patient about recommendations for treatment were noted and converted into interview topics.

A total of 16 physicians were interviewed from among the physicians who recruited the patients. Eight general practitioners and eight (general) oncologists were selected, including younger and older (mean age 49 years, range 29-60), male and female physicians with few to many years of working experience, and from different settings (general practice, university hospital, and general hospital). The interviews were carried out between May and October 2002.

Each physician was interviewed at his or her office. Each interview lasted between 30 and 60 minutes. The interview topics covered the characteristics of the physician; working experience; curative versus non-curative treatment and palliative care in oncology; the physician-patient relationship, especially

concerning treatment decisions; patient autonomy; physician's beneficence; and treatment refusals and their rationality.

All the patient and physician interviews were audio-taped and transcribed. A descriptive qualitative approach was used to analyse the interviews. During the analysis, we used computer software (Kwalitan 5.0) for multiple text management, including coding, locating, and retrieving key materials, phrases, and words. Each interview was divided into several segments. The segments were coded and the codes were organized into categories and put into a tree-structure. A second independent researcher supervised the process of data management.

5.3 'Making decisions' and 'defining life choices'

Over the last decades, patient autonomy has received much attention in relation to patients having the opportunity to choose. Studies about patient participation in decision making almost all refer to choosing between treatment alternatives (review by Guadagnoli and Ward²⁵). Also in ethical theory, patient autonomy considered as the patient's opportunity to choose has been given much emphasis: the liberal understanding of patient autonomy focuses on patient self-determination with the underlying idea of a rational and reasonable person who makes autonomous decisions. Moreover, patient autonomy is often translated into the notion of informed consent, which is directed on patient autonomy as giving patients the opportunity to deliberately choose between treatment alternatives.

Our study corroborates the liberal idea that patient autonomy is related to the opportunity to choose. Our results namely show that when patients refuse oncological treatment, patient autonomy is related to a patient who makes decisions.²³ 'Making decisions' in this context means that patients want to have the opportunity to choose between available treatment options, for example, between the options of receiving oncological treatment, no treatment at all, or no life-prolonging treatment. In this process, the patient-physician relationship plays a crucial role, because it encloses a common component between patient and physician: the patient wants to have the opportunity to choose between options of which the physician informs the patient.

Besides ‘making decisions’, our study stresses that patient autonomy in the context of cancer treatment refusal relates to a patient who defines life choices.²³ ‘Defining life choices’ refers to patients who want to strive for their own individual goals in life. This is related to something particular in the patient’s own life and not so much to available treatment alternatives. We found that when patients are faced with a possible life-threatening disease, they feel that they should have a lot of options other than treatment alternatives.²³ According to MacDonald, exactly this perspective is not enough articulated by the liberal tradition.¹⁰ The standard of informed consent, for example, requires that patients are suitably informed about their prognosis and options, and are allowed to choose among them. Such an approach ignores numerous contextual factors that may prevent patients from experiencing the possibility of real choice.¹⁰ MacDonald uses the feminist work on relational autonomy to argue that attention to the social and contextual factors that facilitate meaningful autonomous action gives an improved understanding of autonomy. This idea is supported by an ethic of care.⁵⁻⁹ Most of the criticism to the liberal understanding of patient autonomy stresses that too much attention is directed to guaranteeing patients’ choices and patients achieving independence.⁸⁻¹⁰ An ethic of care shifts away from achieving independence towards a view that seeks meaningful self-direction within a context of interdependence.⁵⁻⁹

Our study shows that respect for patient autonomy means both guaranteeing patients’ treatment choices and asks for respect for the way patients strive for their own individual goals in life. In our opinion, this indicates that the liberal tradition and an ethic of care do not so much diverge as some suggest. To understand this, we first have to explore the patients’ perspective and the ideas on freedom that are related to patient autonomy in medical decision making.

5.4 A patients’ perspective

An approach that particularly pays attention to a patients’ perspective, is patient-centered medicine. An extensive body of literature has emerged on this subject. Yet, despite popularity of the concept there is little consensus as to its meaning.¹¹⁻

¹⁴ Here, we hold on to an approach of patient-centered medicine that focuses on

“patient participation in clinical decision making by taking into account the patients’ perspective, and tuning medical care to the patients’ needs and preferences.”¹²

Atkins has discussed a patient-centered approach and has related it to respect for patient autonomy.²⁶ She describes that “affective responses are appropriate and needed considerations in the case where one must attempt to assume another’s perspective in order to respect autonomy.”²⁶ Atkins makes a distinction between subjective knowledge (“the subjective character of experience”) and objective knowledge (“a phenomenon in terms of universal laws and categories”).²⁶ She argues that we cannot objectively know what it is like to be another person, no matter how many facts we possess. She particularly pays attention to the patient-physician relationship in this process; especially concerning respect for the way patients incorporate their personal perspective in medical decision making.²⁶ When it comes to respecting patient autonomy, Atkins pleads for a place for both medical knowledge and the patients’ perspective.

In our study, also both objective knowledge and subjective knowledge are apparent in medical decision making. The treatment options presented by the physician can be seen as objective knowledge. ‘Universal laws and categories’ then means ‘generally accepted in medical practice’. Most of the time, physicians’ recommendations for treatment are based on a certain consensus in medical practice on what is the best treatment for a given diagnosis. Objective knowledge thus seems particularly related to ‘making decisions’; a choice between recommended treatment options that are commonly available in medical practice. On the other hand, subjective knowledge is reflected by the patient’s perspective. This perspective consists of considerations and deliberations related to the particular situation of the patient. Our results show that this perspective plays a key role in medical decision making, especially in the way patients strive for their own individual goals in life: most patients who refused oncological treatment wanted to define themselves which characteristics, which conditions, and which choices best fit their goals in life.^{23,24,27} For example, for some patients with breast cancer, losing a breast played an important role in their decision to refuse surgery. Such a decision then is based on an important consideration in the patient’s life: keeping her breast, which may reflect values such as identity, dignity, and/or integrity.

Differences in patients' perspectives seem to make differences in treatment decision. For example, we found that for one patient it is a matter-of-course to visit the hospital and to accept a recommended treatment, because this treatment may stop the growth of the tumour. Another patient refuses the recommended treatment, because he or she just does not want to suffer from all the toxic effects of the treatment with the burden and the dependence on others. It is noteworthy that to the latter patient the earlier described context of dependence seems to play an important role, whereas to the former patient this does not seem to be of importance. This suggests that one cannot determine beforehand whether, in general, patients appreciate independence or not. Furthermore, it suggests that differences in the appreciation of the consequences of the treatment, including how the end of life will be, create differences in treatment decision making. It seems as if the patient's own idea of what is in his or her best interest is closely related to the patient's specific history, experiences, and view on what is important in life, including on how the patient views the end of life. When patients explain why they have made certain treatment decisions, they often refer to experiences related to disease and treatment processes of the patient him or herself or of close others. These experiences seem to serve as a source of knowledge of what can be expected from being treated or not. This knowledge (subjective knowledge according to Atkins) strongly influences patients' decision making. Therefore, in our opinion, understanding a patient's treatment decision includes not only understanding a patient's medical opportunities and prognosis, but includes understanding a patient's perspective as well.

5.5 'Freedom of being' and 'freedom of choice'

If patients deliberately want to make treatment decisions and want to consider whether the recommended treatment is congruent with their own perspective, the concept of freedom is of major importance. Atkins argues that autonomy in the liberal tradition is generally understood as the freedom to pursue one's own conception of the good life. She continues to state that this conception does not mean that people should be left alone to make of their lives as they choose. Instead it means that we should give a place within our collaborative existence for

each other's specific values and differences.²⁶ With this statement, Atkins seems to connect a patient-centered approach to an ethic of care. Ethic of care has as its central theme the responsibilities we take for ourselves and for each other; a relational conception of freedom. So it is not the right to freedom in the sense of the right to non-interference; not an ideal of independency in which a good life is a life in which we do not need the help or support from anyone else in meeting our needs and carrying our life plan.^{5,6,8}

In our study, most patients who refused oncological treatment wanted to have the freedom to choose an option they preferred for themselves. Freedom in this sense includes 'freedom of choice', i.e. the freedom to have the opportunity to choose between available treatment alternatives (including no life-prolonging treatment or no treatment at all). On the other hand, it includes 'freedom of being', in which the patient makes a decision that is congruent with his or her experience and perspective of life. For example, a patient who wants no chemotherapy at all may experience freedom that is defined by freedom to choose between treatment alternatives, but also by freedom that is particularly related to freedom to incorporate his or her own perspective in the decision-making process. This 'freedom of being' is also reflected in the observation that some patients find it really important to take initiatives during their disease. Taking initiatives can be considered as a way to attain or follow individual goals in life. For some patients this may imply that they visit another physician for a second opinion, some patients try to find their way in complementary medicine, and others visit psychosocial support groups.

Our study suggests that 'freedom of choice' is related to the medical information patients obtain from their physician. The results show that patients sometimes do not experience 'freedom of choice' when they have the idea that their physician does not present all treatment options or presents a certain treatment as the standard and finds it self-evidently that the patient will accept the recommendation. This does, however, not mean that by presenting all treatment options a patient automatically experiences 'freedom of choice'. A choice between too many options may for some patients result in total chaos and a loss of freedom.

‘Freedom of being’ is not so much related to medical information, as to the physician’s attitude. In our study, for instance, some patients who refused treatment did not experience freedom in making their own decision or in having the opportunity to strive for their own goals in life. The decision to refuse treatment took a lot of struggling and some felt that an enormous amount of pressure was exerted on them to accept the recommended treatment.²³ These patients did not experience ‘freedom of being’ in their decision to refuse a treatment. Other patients who refused treatment did experience ‘freedom of being’, because they experienced that their physician paid attention to their perspective of life and they experienced having the opportunity to exchange personal values and experiences. It needs to be noticed that not all patients appreciate the ‘freedom of being’ that is described here. Some patients may want the physician to decide for them just on the basis of available treatment options.

The distinction between ‘freedom of choice’ and ‘freedom of being’ seems to resemble the distinction between the ideas on freedom as presented by the earlier mentioned liberal tradition and ethic of care: the liberal understanding of patient autonomy attaches great importance to autonomous choice. An ethic of care stresses a more contextual and narrative appreciation in the patient-physician relationship. Interestingly, in our study, we found that for most patients, both ‘freedom of choice’ and ‘freedom of being’ are important. There does not seem to exist a difference in emphasis put on one of them, although it is noteworthy that particularly in refusing recommended oncological treatment, ‘freedom of being’ is often explicitly expressed. Thus, it seems as if the liberal tradition and an ethic of care articulate a different aspect of the decision-making process, whereas, for patients, both are present.

5.6 A physicians’ perspective

So far, we particularly paid attention to a patients’ perspective in the decision-making process, but what about the physician? Our study shows that when a patient refuses recommended oncological treatment, the physician is faced with questions about the background of the patient’s decision, the patient’s arguments, the acceptability of the decision, and the patient’s role in the decision-making

process.^{24,27} Physicians evaluate a patient's situation, they form an idea of what is in the patient's best interest, and decide what is an appropriate treatment decision. Our results show that whereas patients base their treatment refusal mainly on personal values and experiences, physicians mainly emphasize a medical perspective when evaluating a patient's treatment refusal.^{23,24,27} This medical perspective consists of a coherent system of terminologies, deliberations, and expressions that are common in medical practice, for example, the kind of tumour, the prognosis, and/or the side effects of a certain treatment.^{23,24,27} When medical decisions are to be made, patients become part of this medical perspective and tensions then may develop.

Nowadays, it is clearly established in medicine, ethics, and law that a competent patient has the right to refuse medical treatment. There is no difficulty if a patient's refusal concurs with clinical evaluation, but the issue becomes problematic when a patient's refusal conflicts with medical opinion.²⁸ Tension between a patients' perspective and a medical perspective then becomes visible. A patients' perspective and a medical perspective may show some overlap, but patients' treatment decisions based on personal values and experiences remain most of the time outside a medical perspective. Physicians are inclined to evaluate reasons to refuse a recommended oncological treatment as 'good', 'rational', or 'sensible' from a medical perspective. Consequently, patients' decisions based on personal values and experiences are often interpreted as irrational and difficult to accept.²⁷

In addition to a medical perspective, the personal values of the physician may play a role in the evaluation of a patient's decision.^{24,27} Although from a medical point of view, a patient's decision may not be based on good reasons (since, for example, the decision is based on emotions or on arguments that result from a false impression of things), a physician may still sympathize with the decision: "Why she [patient] does it [refuse treatment] is irrational, but the decision is easy to sympathize with, that's the problem."^{24,27} In this case, the physician seems to give room for the patients' perspective on life, leading to respect and understanding instead of strengthening the tension between the patients' perspective and the medical perspective.

Our study shows that in the physician's evaluation of the patient's treatment refusal it is important whether the decision concerns curative or non-curative treatment (some prefer to make the distinction between curative and palliative treatment, but to forego misunderstanding, we call treatment goals curative and non-curative²⁹). This distinction is important for two reasons: firstly, in their evaluations concerning non-curative treatment refusal, physicians are inclined to give more room to the personal values and experiences of the patient compared to the evaluation of refusal of a curative treatment. Secondly, physicians will exert less pressure to persuade the patient to accept the treatment as recommended in case of non-curative treatment compared to refusal of curative treatment. Physicians find the degree of rationality of patients' arguments less important when it comes to decisions about non-curative treatment compared to decisions about curative treatment.^{24,27}

We argue that particularly physicians' respect for the patient's perspective in the decision-making process is crucial for the patient-physician relationship. Most of the time, physicians are inclined to interpret respect for patient autonomy particularly from the viewpoint of 'freedom of choice': freedom determined by medical information, by offering treatment alternatives. Physicians' respect for patient autonomy seems often not so much to concern 'freedom of being' that relates to the patient's own perspective of life. In our opinion, if the physician pays attention to that perspective, then this will contribute to the patient's feeling of being understood and respected, and thus to a better physician-patient relationship. If, the other way around, the physician does not respect the patient's perspective in the treatment refusal, he or she is often inclined to persist in convincing the patient to accept the treatment.³⁰ The physician may try to convince the patient to agree with the doctor's viewpoint by discussing medical facts in order to ensure that the patient understands his or her situation. This seems to result in patients experiencing that they are not really free to make their decisions, often leading to frustration and miscommunication.

5.7 Discussing a patients' and a physicians' perspective

As earlier described, the liberal tradition is often criticized for only taking into account respect for patients' autonomous choices. Beauchamp and Childress, however, have stated in their *Principles of Biomedical Ethics*: "To respect an autonomous agent is, at a minimum, to acknowledge that person's right to hold views, to make choices, and to take actions based on personal values and beliefs."² This suggests that in the liberal tradition, respect for patient autonomy seems also to include respect for a patients' perspective, including the way patients strive for their individual goals in life. Unfortunately, often too much attention is directed on the respect for the autonomous choices, instead of recognizing a principle of respect for persons, with respect for their autonomous choices being simply one of its aspects.³¹

Respecting a patients' perspective seems not always to be consonant with the portrayal of respecting a rational and reasonable moral agent, which is the underlying idea of the liberal understanding of respect for patient autonomy. However, it is important to see that from both a medical perspective and a patients' perspective good reasons and rational arguments can be given for refusing oncological treatment. As our study indicates, most of the time, only arguments following medical perspective are considered as rational arguments. We argue, however, that in order to maintain or develop a patient-physician relationship in which open communication has an important place, arguments from a patients' perspective need to be respected, as are arguments from a medical perspective. In order to fully respect patient autonomy, physicians need to give weight to the patients' perspective of life and the values belonging to it. Moreover, it is important that physicians identify both decisions on curative treatment and decisions on non-curative treatment as decisions in which it is important to consider a patients' perspective.

To understand that patients' perspective, an ethic of care promotes "a particularistic moral epistemology in which attention, contextual and narrative appreciation, and communication are considered as elements of moral deliberation."⁹ This is in line with the approach of patient-centered medicine on which Clifton-Soderstrom has given an ethical reflection.³² She calls for a person-

centered foundation of medical practice and uses the work of Levinas to show how the dynamics of the patient-physician relationship forms the basis of medicine: "The moral obligation of the physician is imposed by the patient as Other, an obligation that is prior to the interpretive framework of medical knowledge."³² According to Clifton-Soderstrom, the scientific impersonal facts that are important for physicians to have a common set of terms in order to diagnose and treat persons, should not preclude narrative practices. The 'alterity' of the patient as other needs to be recognized. "When one's alterity is not recognized, persons resist medical knowledge, in ways both subtle and overt, because it divest them of their unique humanity. [...] One way of recognizing patients' unique humanity is by hearing their narrative, or their illness framework, on their own terms."³² To come to a convergence of a medical perspective and a patients' perspective, and consequently to a respect for both 'freedom of choice' and 'freedom of being', on the one hand physicians need not to diverge medical information from a patient's perspective. On the other hand, patients need not resist medical information, but need to incorporate the medical information they receive in their own perspective. Thus, in the decision-making process, the relational conception of patient autonomy earlier mentioned and stressed by an ethic of care seems to be relevant: both patient and physician need to make a valuable contribution. Patients contribute by expressing their perspective. On the other hand, physicians contribute as well: in addition to offering (information about) medical technical opportunities, they create the circumstances in which it is easier or more difficult for patients to express their perspective.

Illustrative for this interaction in which both patient and physician contribute, is a dialogue between Starr and Zawacki who discuss Katz's famous book *The silent world of doctor and patient*.^{33,34} Zawacki remarks that neither the doctor's world, nor the patient's world is silent. "The worlds of doctor and patient are separate, busy, noisy planets. It is the vacuum between them that is silent."³³ Listening and dialogue can breach that vacuum as such that doctor and patient may breath the air of each other's world.³³

5.8 Summary and conclusion

Our results suggest that, in the context of cancer treatment refusal, patient autonomy can be understood as the opportunity to direct one's own decisions and to direct one's own life. For a patient, his or her own perspective, including his or her own personal values and experiences, forms the basis of the treatment decision. This perspective goes beyond the recommended treatment alternatives and can only be known and interpreted by listening to the patient. Respect for patient autonomy therefore means both guaranteeing patients' choices ('freedom of choice'), and asks for respect for the way patients strive for their own individual goals in life ('freedom of being'). In the patient-physician relationship, difference in emphasis exists and appears to be problematic: physicians particularly articulate 'freedom of choice' and patients want to be respected in both 'freedom of choice' and 'freedom of being'.

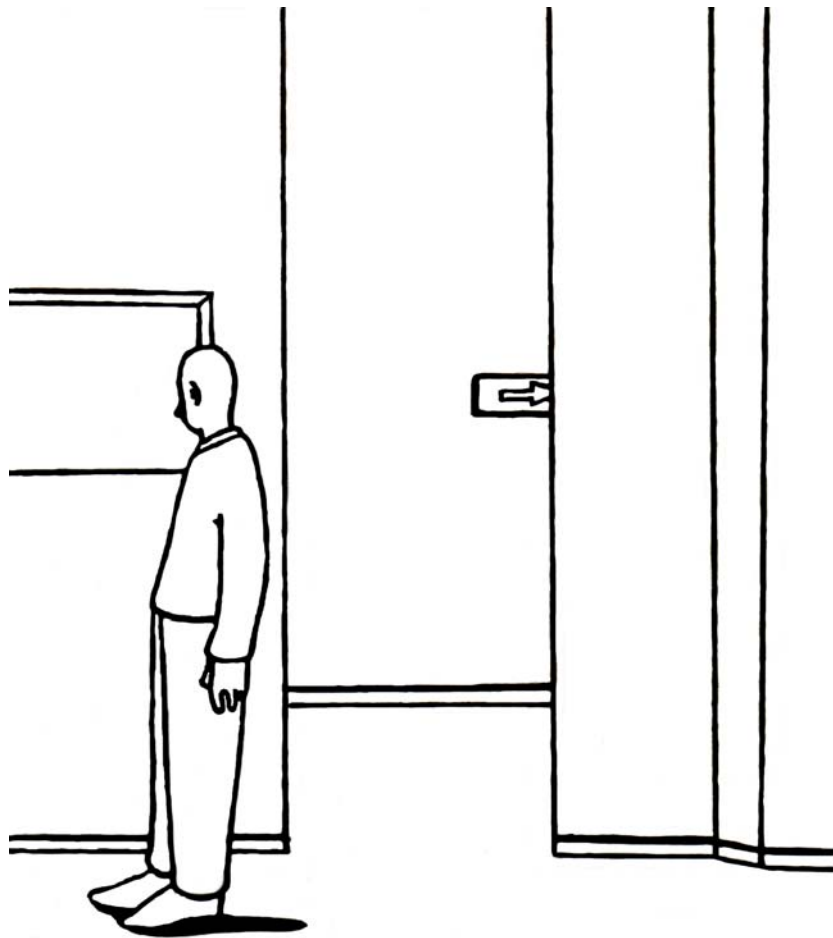
The liberal tradition has been criticized for not giving enough attention to a patients' perspective and for only paying attention to the patient's opportunity to choose. Respect for a patients' perspective is, however, included in the liberal understanding of patient autonomy, although indeed not so much emphasized. In addition, the liberal tradition is criticized for being too individualistic. Instead, an ethic of care and the approach of patient-centered medicine consider a more relational basis of patient autonomy. We showed that in the context of cancer treatment refusal, relationality is present in both guaranteeing patients' choices and in respect for the way patients strive for their own individual goals in life. Thus, in our opinion, the liberal understanding of patient autonomy and an ethic of care do not so much diverge as the critics suggest, at most a difference in emphasis exists. Combining the two perspectives may give optimal directions for a patient-physician relationship in which there is attention for choice between treatment alternatives, and for both the patient's and the medical perspective. Listening and dialogue in which both patient and physician are present can reach this.

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General discussion



General discussion

This thesis gives an ethical exploration of treatment refusal in clinical oncology. The objectives of the study were twofold: firstly, to provide insight into patients' and physicians' considerations concerning treatment refusal in clinical oncology. Secondly, to clarify the concept of patient autonomy in the context of cancer treatment refusal. The main research question of the study was: how does the concept of patient autonomy take shape in the decision-making process on oncological treatment, particularly in cases of treatment refusal? The focus was among others on (1) the motives of patients to refuse recommended oncological treatment, (2) physicians' attitudes to treatment refusal, and (3) the position of the patient and the role of the physician in the decision-making process, with a special focus on issues of patient autonomy. In this general discussion, methodological considerations are given, the results of the study are put into perspective, and the research question is discussed.

Methodological considerations

Given that one of the central aims of the study was to examine a relatively unexplored area, it was decided to use a qualitative approach.^{1,2} The ability of qualitative methods to obtain in-depth information and to generate 'thick descriptions' of situated experience, seemed to be an ideal way of addressing the objectives of the study. The study started with a global formulation of the problem, followed by the first observations in an oncological outpatient clinic. Subsequently, interviews were carried out and analytical and reflectional activities alternated. Important aspects from the interviews were further explored and analysed. The results were interpreted and were related to existing theories in the field of research. An important characteristic of the study is the relatively open explorative research character: it did not use an explicit observational or coding scheme that was specified beforehand, the study did not depart from an analytical framework, and no hypotheses were tested. The open explorative character has the advantage of signalling considerations, attitudes, and related factors that were not thought to be present beforehand. Another advantage is that during the interviews

the open explorative approach stimulated respondents (patients and physicians) to mention all kinds of aspects related to their decision-making process. The respondents were not restricted by, for example, a list of considerations that could relate to their decision-making process.

Qualitative studies, like this one, may also show some shortcomings. The following issues are discussed here: (1) the selective group of respondents, (2) the number of respondents, (3) desirable answers and accounting practice, and (4) the absence of a one on one match between patient and physician.

Selective group of respondents

The group of respondents who participated in the study is a selective group. The physicians are not representative of all physicians in the Netherlands who work with cancer patients: they were selected from six hospitals and from general practices in and near Amsterdam. The patients are not a representative random selection of all cancer patients in the Netherlands. In the study almost all patients are white Dutch, a large group of patients have high educational levels, a number of patients were obtained from associations for cancer patients, only a selection of all possible cancer diagnoses is present, and the distribution of cancer diagnoses in the study is not the same as it is in the Dutch cancer population (for instance, men with lung cancer are underrepresented). Moreover, a bias may have occurred in that patients who talk more easily about their disease are probably also earlier inclined to respond to the call to participate. This bias is likely to be present both in the group of patients recruited by physicians and in the group of patients from the patient associations. Related to this response bias, a gender bias may have occurred: more women than men participated in the study.

Because the study is based on a selective group of respondents, the ability to generalize the results to larger populations is limited. The results still can be considered as paving the way for further large-scale studies. The group of respondents was diverse enough for the purpose to explore and observe interesting differences between the respondents. At the same time, the group of respondents was compact enough to reach data satisfaction³ using qualitative methodology: at the end of the study (during the last interviews), no new

information on the subject of interest was yielded. Data satisfaction is important when making use of qualitative research methods.¹⁻³

Small numbers

The number of respondents in the study (30 patients who had refused treatment, 22 patients who had accepted treatment, and 16 physicians) is sufficient for qualitative research methods to reach data satisfaction.³ Still, for quantitatively based conclusions the numbers are small. An important limitation of working with a small number of respondents is that explanatory conclusions cannot be drawn. The present study did not strive to be explanatory. The study describes observations and interprets them. To prevent subjective interpretations, all interviews were audio-taped and transcribed, the analysis was structured by using computer software (Kwalitan 5.0), and a second independent researcher supervised the process of data management.

Another limitation of the study due to the small numbers is that patients were split up into groups only on the basis of the goal of the recommended treatment (curative or non-curative). We could not use other characteristics to split up patients into groups. In future research with larger populations of patients, it may be interesting to stipulate differences between men and women in the context of cancer treatment refusal, because men and women are known to have different styles of coping with a distressing situation.⁴ Moreover, women are known to be more active in medical decision making than men.⁵ In addition to differences between men and women, it is interesting to know more about the decision-making process of patients who refuse treatment from the beginning compared to those who begin treatment and choose to stop, and to know more about patients who refuse all treatment compared to those who refuse only a part of a recommended treatment.

Desirable answers and accounting practice

Results of studies that make use of interviews may be influenced by respondents who give desirable answers or by respondents who give motives for their decisions that are influenced by accounting practice. In answering the questions raised by the interviewer, respondents may give answers that are not exactly

conform how they really acted or conform the motives that really played an important role in their decision-making process. Respondents may want to justify a decision they made on the basis of feelings or intuition. Consequently, they may not tell the real reasons for their decision and motivate their decision with, for example, arguments that are supported by a majority of the population. A possible reason for this is that these arguments are more easily put into words, are simpler to understand, or that others will ask less difficult questions. The real motivation for the respondent's decision may then be different from what the respondent has put forward. Qualitative interview techniques provide the possibility to verify the respondent's answers. In the present study, the respondent was, for example, asked to give an example or description that was applicable for his or her situation. Moreover, the interviewer was trained to recognize desirable answers or accounting practices. If desirable answers or accounting practices were recognized, those were related to answers given by the respondent earlier in the course of the interview and discussed with the respondent.

No patient-physician match

Finally, the study can be criticized for not having linked the patient and physician interviews to each other. Mostly, not the attending physician of a patient who participated in the study was interviewed. For a sound history of the decision-making process between a particular physician and patient it would have been better to have a one on one match between patient and physician. In the present study, we did not strive to have information that was particularly related to the decision-making process of the patient's attending physician. We strived to have the patient interviews as confidential as possible. We wanted to assure the patient that no information from the interview would be discussed with the attending physician. Hence, the patient could be stimulated to speak openly about all kinds of aspects related to the decision-making process, including the patient-physician relationship. To increase confidentiality, the interviews were carried out at a place where the patient preferred to be interviewed and anonymity in analysis and publication was guaranteed.

Discussion

In the following section, the results of the study are put into perspective. Moreover, the main research question of the study is discussed: how does the concept of patient autonomy take shape in the decision-making process on oncological treatment, particularly in cases of treatment refusal?

The patient-physician encounter

The starting point for treatment decision making in clinical oncology is the encounter between the patient and the physician. The patient-physician relationship is shaped by the goals of that encounter, both the goals of the physician and the goals of the patient. These goals are multi-faceted. The goals of the physician are directed to provide good medical care: cure the patient or, when cure is not possible, provide palliative care. The other person in the encounter is the patient, who also has his or her own goals, both health-related goals and broader goals in life, as well as values and preferences. The goals of physician and patient may show overlap, but may sometimes also be incompatible (Chapter 2). The reasons why patients refuse an oncological treatment are diverse. Both medical and personal considerations seem to play a role in the patient's decision-making process. For example, patients find it important not to be ill due to the treatment, to stay in control, not to spend valuable time in the hospital (Chapter 2), or they emphasize reasons related to their end of life (Chapter 3). Acceptance or refusal of oncological treatment corresponds to different end-of-life attitudes of patients (Chapter 3). The study shows that physicians mainly emphasize the medical perspective when evaluating patients' treatment refusals: the kind of tumour, the prognosis, and/or the side effects of treatment (Chapter 2). The differences in perspective between patient and physician sometimes result in tension.

The patients' perspective

In medical decision making, taking into account the patient's perspective is not always easy: each person forms his or her own conception of what is a good life and each person has the freedom to put the choices that arise from that

conception into effect, provided those choices do not harm others. This is the twofold basis of autonomy described in this thesis, namely as 'making decisions' (freedom of choice) and 'defining life choices' (freedom of being, Chapter 4 and 5). Making decisions entails the patient's opportunity to choose between available treatment options and is related to the medical information patients obtain from their physician. Defining life choices refers to patients who want to strive for their own individual goals in life and is related to the physician's attitude: the way the physician pays attention to the patient's perspective of life and whether or not the physician exerts pressure on the patient to accept the recommended treatment.

Since each person can form his or her own conception of what is a good life and accordingly makes decisions, it seems as if autonomy can only be valued within the particularity of each situation; based in an understanding of where that autonomy is derived from: the patient's goals and personal conception of what is a good life. This personal conception may not always be in accordance with a medical perspective on what is best for the patient. Differences in ideas on what is best for the patient may then result in tension around the patient-physician encounter. Tension that may arise between a patient's own individual perception of what is best for him or her and a more generalized perception of what is generally seen as good in medical practice (Chapter 2).

The tension between patient and physician results among others from differences in the standards of rationality that patients and physicians use in the decision-making process (Chapter 2). Physicians mainly use goal-oriented rationality based on a general moral point of view while patients mainly use value-oriented rationality based on a circumstantial basis. It has been shown that patients' treatment decisions based on personal values and experiences fall most of the time outside a medical perspective and are judged by physicians as irrational. If physicians give more emphasis to value-oriented rationality, a consensus between the value-oriented approaches of patient and physician may emerge. That consensus may lead to a better understanding of the patient's decision and acceptance by the physician. It has been discussed that the issue concerning differences in the standards of rationality used, is less problematic if physicians interpret good reasons to refuse a recommended oncological treatment from both a medical and a patients' perspective based on specific values (Chapter

2). This touches on the approach of moral reasonability as described by Scanlon.⁶ Scanlon argues that a rational person is, first of all, a reasoning person – one that has the capacity to recognize, assess, and be moved by reasons, and hence have judgment-sensitive attitudes. Irrationality occurs when a person recognizes something as a reason but fails to be affected by it. For example, when a person fails to do something even though he or she judges there are good reasons to do it.⁶ The failure to give weight to considerations of one's own well-being is generally considered as the prime example of irrationality. Scanlon argues that the question is not whether a certain action or desire of a person is irrational, but whether it is open to rational criticism. Does a person have reasons or not. The reasonableness of a belief or an action may be assessed relative to the person's beliefs at the time and the reasons he or she sees as relevant. A belief or action is mostly judged unreasonable relative to the way a person is reasoning from a shared body of information and conception of the relevant considerations or relative to the way that person is ignoring facts or reasons.⁶

Concerning cancer treatment refusal, patients are often said to ignore facts or reasons. For example, the study shows that patients are said to make a disproportional decision since the burdens of treatment (e.g., loss of hair and/or nausea) do not outweigh the benefits (e.g., life-prolonging or cure). Consequently, physicians are inclined to provide patients with medical information about side effects and the consequences of not having treatment, whereas patients may have non-medical motives to refuse treatment (Chapter 2). In line with Katz⁷, we argue that insufficient attention is given to the unconscious and irrational motivations of behaviour. Physicians and patients must engage in conversations in which the patient's and the physician's perspective are discussed.

To improve the quality of care, physicians should understand their patients' perspective. This raises many challenges for physicians. Practical concerns include time pressure and difficulties in eliciting perspectives from patients who may be hesitant to make treatment decisions.⁸ These are compounded by a deficit of appropriate information to support patients' decisions.⁸ The healthcare sector has used a range of methods to identify the perspectives of patients. Examples are questionnaires with the physician, shared decision-making models, focus groups with patients to include their views in clinical guidelines, and surveys

among patients to provide feedback to care providers.⁹ Many of the methods mentioned have not been shown to be valid or effective.⁹ The evaluation of specific methods to obtain the perspectives of patients therefore requires further research. Moreover, in medical training increased emphasis needs to be given to communicative skills and to stimulating a positive attitude towards psychosocial and existential issues present in the patients' perspective. In addition, patients themselves need to be encouraged to take an active part in their decision-making process by raising questions and discussing issues that are important to them.

Balancing medical information

Physicians are increasingly encouraged to involve patients in treatment decisions, recognizing patients as experts with their unique knowledge of their own health and their preferences for treatments, health states and outcomes.^{8,10} Increased patient involvement is an important part of quality improvement since it has been associated with improved health outcomes and enables physicians to be more accountable to the public.^{8,11} However, this involvement also poses challenges for physicians.⁸ It is not always easy to give attention to a patients' perspective. One cannot rely on protocols, a general standard, or something that is common to do. The physician needs to investigate why the patient takes an 'illogical' position (Chapter 2) and has continuously to anticipate on the particularity of the patient's situation: what kind of patient is the patient who visits the physician, which experiences with disease and treatment takes the patient with him or her? Kodish and Post argued that physicians should respond to the individualized needs of each patient.¹² Whether this is feasible in medical practice remains unclear in their work. What seems to be feasible is an exploration of those individualized needs of patients. The results of this study show that in the decision-making process on oncological treatment, it is important that physicians first explore the patient's perspective, before giving further medical information (Chapter 4). This entails that patients' own goals in life, their ideas about the end of their life (Chapter 3), and preferences concerning medical treatment and the provision of information are discussed. In other words, patients need to be approached as experts. According to Shaw and Baker, "all patients are experts, however uninformed or misinformed they may be about health issues. Patients' expertise is valuable because by

understanding the patient's views and situations, the doctor is better equipped to identify a solution that will lead to a successful outcome, however defined".¹³

The exploration of the patient's perspective requires that the physician ensures that the patient correctly understands his or her situation with regard to the disease the patient is suffering from and the treatment opportunities that are available. Therefore, the ideas of patients about having cancer and being treated need to be clarified. In decision making, patients often rely on what they have heard and seen about having cancer and being treated. In these experiences, they often seem to mix up ideas about diseases and treatment (Chapter 2 and 4). Physicians then need to clarify that, for example, breast cancer is different from intestinal cancer and that chemotherapy for the former is also different from chemotherapy for the latter. Only when those misconceptions are exposed and discussed, the information given to patients will be properly precipitated, resulting in informed patients who are able to make decisions.

The study shows that it is of crucial importance that in providing information to patients, the various goals of treatment and care are clarified. That clarification is an indication for patients to know in which phase of the disease they are (Chapter 1), it influences the grade of toxicity of a treatment that is acceptable for the physician and for the patient (Chapter 1), and it strongly influences physicians' attitudes towards treatment refusal (Chapter 1, 2, 4). Clearness about treatment goals stimulates a good communication between patient and physician. Another reason is that close consideration of used terminologies contributes to transparency in the cooperation between physicians. Every physician will then provide the same information to the patient.

In clinical oncology, however, the distinction between curative and palliative treatments seems to be problematic (Chapter 1). For example, often the physician knows very well what he or she means using the term 'palliative', but the word 'palliative' may be interpreted in a more favourable way by patients (see also the studies of The et al.¹⁴ and Koedoot¹⁵). Miscommunication and misunderstanding about the goal of the recommended treatment being curative or palliative may result in tension during the patient-physician encounter. Calling treatment goals non-curative instead of palliative seems to be one solution of the problem of miscommunication and misunderstanding (Chapter 1). However, the distinction

between curative and non-curative treatments then still is problematic. For some physicians and patients the distinction will remain a grey area: a lot of uncertainties exist about the curative effects of certain treatment and/or about the cut-off point of calling a treatment curative or non-curative. In such cases, communication mostly concerns scientific uncertainties and/or how to interpret percentages. On the other hand, if treatment goals are clear, some patients may, for example, insist on their belief of the curative opportunities of the treatment, although they receive non-curative treatment. For physicians, it is very hard to evaluate whether they should continue in those cases to repeat that the goal is non-curative. The hope of the patient may after all positively influence the disease process and should not be swept away. Physicians need to balance the obligation to be honest with an equally important duty to cultivate hope.¹²

A related balancing process can be observed in the presentation of treatment options to a patient as such that he or she is able to deliberately make a choice (freedom of choice, Chapter 4 and 5). The present study shows that patients find it important to have the opportunity to choose between treatment options; between, for example, the option not-to-treat. Patients who refused treatment indicated not to have the opportunity to choose when the recommended treatment was presented as the standard treatment or when the option not-to-treat was not presented as an option. However, in giving patients the opportunity to choose, physicians must balance the amount of information that is provided to patients: too little information may cause that patients do not experience the opportunity of real choice, and too much information may cause chaos, leading also to a difficult decision-making process.

In the above, it is the physician who is able to set limits to the provision of information. The physician judges the situation and may, for example, in some cases decide that not much emphasis should be given to the fact that a treatment is non-curative. Sometimes, the physician makes a selection in the information that is provided to the patient, because by giving too much information, the patient may be overwhelmed and may not be able to handle the situation anymore. Consequently, the physician's considerations with regard to the provision of information and his or her way of providing information may determine the freedom the patient has in the decision-making process (Chapter 4 and 5).

Interestingly, nowadays, in medical practice, there are new developments in the patient-physician encounter. Patients more and more gather information from the internet and visit their physician with this information in mind. For example, patients ask for treatments that are developed or are already in use in other countries. In these cases, physicians are not able anymore to set limits to the provision of information. It would be interesting to investigate what patient autonomy entails if patients, instead of refusing oncological treatment, claim oncological treatment they found on the internet. Treatment decision-making processes will then shift from the physician as gatekeeper of medical information towards the physician as gatekeeper of medical treatment.

Conclusion

The results show that in the decision-making process on oncological treatment patient autonomy takes shape in the way patients make decisions and define their own life choices. In this context, patient autonomy is related to the way physicians take into account a patients' perspective (freedom of being) and to the way physicians provide medical information (freedom of choice). An important condition for patient autonomy to flourish in the fullest way possible is that patients' personal values, experiences, ideas (including those about the end of life), convictions, and fears, are discussed and medical information is tuned to the patient's perspective. Only then patients can deliberately make an informed decision that is congruent with their own perspective of life. Concerning the incorporation of a patients' perspective and the provision of medical information, clearly a multitude of challenges exist for the physician. The physician balances hope with the obligation to be honest, the obligation of giving all information with the risk of causing chaos, and the physician balances the patient's own individual perception of what is best for him or her with a more generalized perception of what is generally seen as good in medical practice. Particularly when a patient refuses recommended oncological treatment it may be difficult to balance the concept of patient autonomy with the desire to provide optimal medical care.

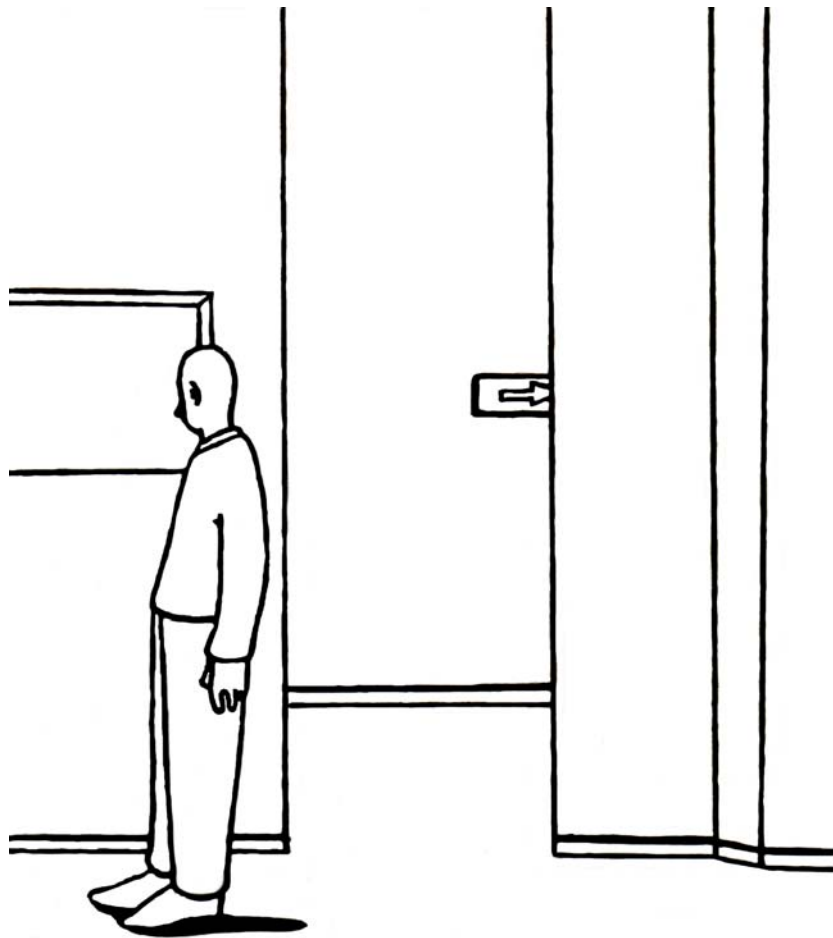
A physicians' response to treatment refusal needs to honour all ethical aspects of the unique context of the interaction between the physician and the patient: the

purpose of health care and treatment, the benefits and burdens of treatment, and, last but not least, the patient's perspective. A wise response to refusal of recommended oncological treatment can thus only be found in the particularity of each situation. Giving a patients' perspective a more prominent role in medical decision making asks for a role of the physician that is directed at both the medical opportunities in decision making and at getting insight into patients' motives for certain treatment decisions. Making a 'yes' or 'no' statement about the irrationality of the decision to refuse the recommended treatment is not the solution. It may only result in a strengthening of the tension between patient and physician. Exploring the patient's perspective, asking what the expectations of the recommended treatment are and discussing these expectations seem to be more in line with a patient-physician relationship in which there is respect and understanding. This makes treatment decision making a unique balancing process instead of a 'slam-dunk'.

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Summary



Summary

Decision making in clinical oncology: an ethical exploration of cancer treatment refusal

This thesis gives an ethical exploration of treatment refusal in clinical oncology. The objectives of the study were twofold: firstly, to provide insight into patients' and physicians' considerations concerning treatment refusal in clinical oncology. Secondly, to clarify the concept of patient autonomy in the context of cancer treatment refusal. The main research question of the study was: how does the concept of patient autonomy take shape in the decision-making process on oncological treatment, particularly in cases of treatment refusal? The focus was among others on (1) the motives of patients to refuse recommended oncological treatment, (2) physicians' attitudes to treatment refusal, and (3) the position of the patient and the role of the physician in the decision-making process, with a special focus on issues of patient autonomy.

Chapter 1

Chapter 1 describes the indistinctness and misunderstandings surrounding the use of the term 'palliative' in clinical oncology. When discussing the start, continuation, or finish of treatment, it is for both physician and patient important to know what the goal of a certain treatment is. Therefore, it is necessary to know what is meant with the used terminologies. The objective was to clarify the term 'palliative' in clinical oncology.

The results show that in clinical oncology, the term 'palliative' is used in two ways. Firstly, to describe palliative treatments and care as described in the palliative care definition of the World Health Organization. Those treatments are directed at pain and symptom relief. Secondly, in clinical oncology, the term 'palliative' is used to describe non-curative tumour-directed treatments. Those treatments are directed at both symptom relief and at controlling the underlying disease, but may also have side effects. Both approaches of the term 'palliative' appear to be mixed up, whereas, clear differences between the two approaches

can be distinguished. Diversity in treatment goals and effects make the use of the term 'palliative' in clinical oncology disputable. The contamination of the term 'palliative' with the inflicted symptoms of toxicity of oncological treatments and possible worsening conditions of quality of life is problematic. The transition from curative to palliative treatment may be obscured when symptom-oriented palliative treatments are in fact tumour-directed. Moreover, the fact that the same anti-cancer treatments can be given to patients with palliative or curative intention is confusing.

In Chapter 1, it is concluded that if we want to define an oncological treatment as palliative, then side effects endangering quality of life should be avoided. Although a non-curative oncological treatment may be palliative, to forego miscommunication, goals should be called non-curative. Clarity about the term 'palliative' in clinical oncology is of crucial importance for the treatment decision-making process. Close consideration of the use of the term 'palliative' will help to clarify the various goals of treatment and care in oncological practice. This stimulates a good communication with the patient. Furthermore, close consideration of used terminologies contributes to clearness in the cooperation between physicians.

Chapter 2

In Chapter 2, physicians' evaluations of patients' decisions to refuse oncological treatment are discussed. Often a physician's evaluation of a patient's treatment refusal is directed to the question: is the patient's decision rational or not? The actual standards of rationality in these cases, however, are not clear. The question therefore arises: on what basis do physicians distinguish between their patients' rational and irrational arguments? The objective of this chapter was to gain insight into the standards of rationality that physicians use when evaluating patients' treatment refusals.

The results show that patients base their treatment refusals mainly on personal values and/or experience. Physicians mainly emphasize the medical perspective when evaluating patients' treatment refusals. From a medical perspective, a patient's treatment refusal based on personal values and

experience is generally evaluated as irrational and difficult to accept, especially when it concerns a curative treatment. Physicians have different attitudes towards non-curative treatments and have less difficulty accepting a patient's refusal of these treatments. Thus, an important factor in the physician's evaluation of a treatment refusal is whether the treatment refused is curative or non-curative.

Physicians mainly use goal-oriented rationality and patients mainly value-oriented rationality, but in the case of non-curative treatment refusal, physicians give more emphasis to value-oriented rationality. A consensus between the value-oriented approaches of patient and physician may then emerge, leading to the patient's decision being understood and accepted by the physician. The physician's acceptance is crucial to his or her attitude towards the patient: if a physician does not accept the treatment refusal, he or she is often inclined to persist in convincing the patient to accept the treatment. This results in patients experiencing that they are not really free to make their decisions, leading to frustration and miscommunication. If a physician does accept a patient's treatment refusal, this will contribute to the patient's feeling of being free to decide, to be understood and respected in his or her decision, and thus contribute to a better physician-patient relationship.

Chapter 3

Patients' decisions on accepting or refusing oncological treatment are influenced by several factors. A factor that needs more understanding concerns the end-of-life attitude of the patient. Chapter 3 discusses patients' attitudes regarding death and dying in relation to their treatment decision.

Seven end-of-life attitudes were distinguished: fighting death, avoiding death, fearing death, fearing dying, making (funeral) arrangements, controlling death, and accepting death. A majority of the patients who had refused treatment also accepted death. They particularly focused on the end of their life. A majority of the patients who had accepted treatment fought against death or avoided death. They focused on how to stay alive and how to define life choices. They regarded their treatment as life-prolonging and death-postponing. Having a social network seemed to be important in accepting treatment. Accepting or refusing treatment

appeared not to be related to fear of death or fear of dying. A desire for euthanasia, however, appeared to be related to fear of dying. Both patients who refused and who accepted treatment mentioned euthanasia. Patients desired euthanasia because they wanted to stay in control and did not want to be dependent on physicians.

In Chapter 3, it is concluded that acceptance or refusal of oncological treatment corresponds to different end-of-life attitudes of patients. Knowledge of the end-of-life attitudes of a patient in an early stage of disease may help physicians to understand patients' decisions regarding oncological treatment.

Chapter 4

Chapter 4 discusses the principle of patient autonomy. Nowadays, the idea that patients should take up an autonomous position in the decision-making process is generally appreciated. Chapter 4 aimed to clarify how the concept of patient autonomy can be applied to patients who refuse a recommended oncological treatment. Focus questions were: (1) what is meant by patient autonomy, i.e. how is this autonomy conceptualized and (2) which factors influence patient autonomy.

The results show that patient autonomy was revealed to be a comprehensive concept with elaborations on 'making decisions' and 'defining life choices' as sub-concepts of patient autonomy. In contrast to what is generally believed, decisions of patients to refuse an oncological treatment do not so much rely on the medical information about disease and treatment options, but are rather inspired by patients' own experiences or those of close others. The medical information and the role of the physician do, however, influence patients' experiences of having a choice ('freedom of choice', dependent on the information given to the patient) and/or being free ('freedom' without referring to choices, but dependent on the intervention of physicians in the decision making process). The results show that the extent of pressure physicians will exert to persuade the patient to be treated as recommended depends on the medical distinction between a curative and a non-curative treatment goal. It seems that there exists a shift in respecting patient autonomy, which depends on factors like treatment goal. It is suggested that

discussing the respect shift may serve to clarify underlying thoughts and principles in the decision-making process for both physicians and patients.

Chapter 5

Chapter 5 offers a more comprehensive, ethical-philosophical elaboration on patient autonomy. It is discussed how the results of the empirical study on cancer treatment refusal relate to the liberal understanding of patient autonomy, to the perspective of an ethic of care, and to the approach of patient-centered medicine. The focus was on (1) patient autonomy as ‘making decisions’ and ‘defining life choices’, (2) the idea of freedom that is attached to patient autonomy, and (3) a patients’ and a physicians’ perspective in medical decision making.

In the context of cancer treatment refusal, patient autonomy can be understood as the opportunity to direct one’s own decisions and to direct one’s own life. Respect for patient autonomy therefore means both guaranteeing patients’ choices (‘freedom of choice’), and asks for respect for the way patients strive for their own individual goals in life (‘freedom of being’). In the patient-physician relationship, difference in emphasis exists and appears to be problematic: physicians particularly articulate ‘freedom of choice’ and patients want to be respected in both ‘freedom of choice’ and ‘freedom of being’. The liberal tradition has been criticized for not giving enough attention to a patients’ perspective and for only paying attention to the patient’s opportunity to choose. Respect for a patients’ perspective is, however, included in the liberal understanding of patient autonomy, although indeed not so much emphasized. In addition, the liberal tradition is criticized for being too individualistic. Instead, an ethic of care and the approach of patient-centered medicine consider a more relational basis of patient autonomy. It is shown that in the context of cancer treatment refusal, relationality is present in both guaranteeing patients’ choices and in respect for the way patients strive for their own individual goals in life.

Chapter 5 concludes to state that in the context of cancer treatment refusal, the liberal understanding of patient autonomy and an ethic of care do not so much diverge as the critics suggest, at most a difference in emphasis exists. Combining the two perspectives may give optimal directions for a patient-physician

relationship in which there is attention for choice between treatment alternatives, and for both the patient's and the medical perspective.

General discussion

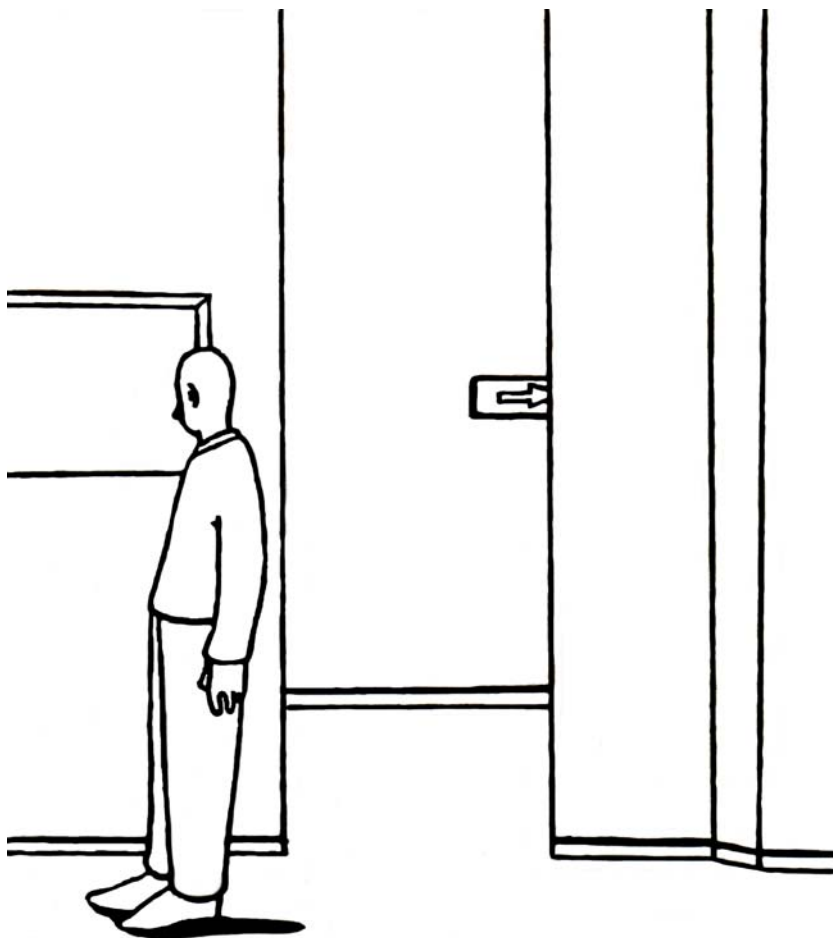
In the general discussion, some methodological considerations are given, which focus on the open explorative character and on some shortcomings of the qualitative study. The open explorative character has the advantage of signalling considerations, attitudes, and related factors that were not thought to be present beforehand. Another advantage is that during the interviews, the open explorative approach stimulated respondents (patients and physicians) to mention all kinds of aspects related to their decision-making process without being restricted by, for example, a list of considerations that could relate to their decision-making process. Qualitative studies, like this one, may also show some shortcomings. Discussed are: (1) the selective group of respondents, (2) the number of respondents, (3) desirable answers and accounting practice, and (4) the absence of a one on one match between patient and physician.

Furthermore, the results of the study are put into perspective and the main research question of the study is discussed: how does the concept of patient autonomy take shape in the decision-making process on oncological treatment, particularly in cases of treatment refusal? The focus is on the patient-physician encounter as the starting point for treatment decision making in clinical oncology. In the decision-making process on oncological treatment patient autonomy takes shape in the way patients make decisions and define their own life choices. In this context, patient autonomy is related to the way physicians provide medical information (freedom of choice) and to the way physicians take into account a patients' perspective (freedom of being). Difficulties and challenges concerning the provision of information to patients and concerning taking into account a patients' perspective are discussed and suggestions for future research and medical training are given.

It is concluded that concerning the provision of medical information and concerning taking into account a patients' perspective, clearly a multitude of challenges exist for the physician. A physicians' response to treatment refusal

needs to honour all ethical aspects of the unique context of the interaction between the physician and the patient: the purpose of health care and treatment, the benefits and burdens of treatment, and, last but not least, the patient's perspective. A wise response to refusal of recommended oncological treatment can thus only be found in the particularity of each situation. This makes treatment decision making a unique balancing process instead of a 'slam-dunk'.

Samenvatting



Samenvatting

Besluitvorming in de klinische oncologie: een ethische exploratie van de beslissing van patiënten om af te zien van een oncologische behandeling

In dit proefschrift wordt een ethische exploratie beschreven van de beslissing van patiënten om af te zien van een oncologische behandeling. Het doel van het onderzoek was tweeledig: ten eerste om de overwegingen van arts en patiënt betreffende het afzien van een oncologische behandeling inzichtelijk te maken. Ten tweede om het concept patiënten autonomie in de context van patiënten die afzien van een oncologische behandeling te verhelderen. De belangrijkste onderzoeksvraag was: hoe krijgt het concept patiënten autonomie gestalte in het besluitvormingsproces betreffende een oncologische behandeling, met name wanneer patiënten afzien van behandeling. De aandacht was onder meer gericht op (1) de redenen van patiënten om van een aanbevolen oncologische behandeling af te zien, (2) de houding van de arts ten aanzien van de beslissing van patiënten om af te zien van een oncologische behandeling, en (3) de positie van de patiënt en de rol van de arts in het besluitvormingsproces, met speciale aandacht voor onderwerpen die te maken hebben met de autonomie van de patiënt.

Hoofdstuk 1

Hoofdstuk 1 beschrijft onduidelijkheden en misverstanden rondom het gebruik van de term ‘palliatief’ in de oncologische praktijk. Wanneer er gesproken wordt over het beginnen, doorgaan of stoppen van een behandeling is het voor arts en patiënt belangrijk te weten wat het doel van een bepaalde behandeling is. Daarom is het noodzakelijk om goed voor ogen te hebben wat er bedoeld wordt met de gebruikte terminologieën. Er is gepoogd de term ‘palliatief’ in de klinische oncologie te verhelderen.

De resultaten laten zien dat de term ‘palliatief’ in de klinische oncologie op twee manieren wordt gebruikt. Ten eerste om palliatieve behandelingen en zorg aan te duiden zoals beschreven in de definitie van de World Health Organization.

Deze behandelingen zijn gericht op pijn- en symptoombestrijding. Ten tweede wordt de term 'palliatief' in de klinische oncologie gebruikt voor niet-curatieve op de tumor gerichte behandelingen. Deze behandelingen zijn gericht op symptoombestrijding en op het controleren van de onderliggende ziekte, maar kunnen ook bijwerkingen hebben. Beide benaderingen blijken door elkaar te worden gebruikt, terwijl er duidelijke verschillen bestaan. De verscheidenheid in behandelingsdoeleinden en -effecten maken het gebruik van de term 'palliatief' discutabel. Het is problematisch dat de term 'palliatief' wordt geassocieerd met symptomen van toxiciteit en met een mogelijke verslechtering van kwaliteit van leven. De overgang van curatieve naar palliatieve behandeling wordt onduidelijk wanneer op symptomen gerichte palliatieve behandelingen in feite op de tumor gerichte behandelingen zijn. Bovendien is het verwarrend dat een zelfde oncologische behandeling een curatief of een palliatief doel kan hebben.

In hoofdstuk 1 wordt geconcludeerd dat wanneer we een oncologische behandeling palliatief willen noemen, bijwerkingen die de kwaliteit van leven in gevaar brengen, dienen te worden vermeden. Ook al kan een niet-curatieve oncologische behandeling palliatief zijn, om miscommunicatie te voorkomen, zou het doel van de behandeling als niet-curatief moeten worden aangeduid. Helderheid over de term 'palliatief' in de klinische oncologie is een belangrijke vereiste voor het besluitvormingsproces. Een weloverwogen gebruik van de term 'palliatief' kan helpen bij het verhelderen van de verscheidene doeleinden van behandeling en zorg in de oncologische praktijk. Dit stimuleert een heldere communicatie met de patiënt. Verder draagt het bij aan duidelijkheid in de samenwerking tussen artsen.

Hoofdstuk 2

In hoofdstuk 2 wordt ingegaan op oordelen van artsen over de beslissing van patiënten om af te zien van een oncologische behandeling. Het oordeel van de arts betreft vaak de vraag of de beslissing van de patiënt rationeel is. Echter, de standaarden van rationaliteit in deze gevallen zijn niet helder. De vraag is daarom op grond waarvan artsen onderscheid maken tussen rationele en irrationele argumenten van patiënten. Het doel van dit hoofdstuk was inzicht te krijgen in de

standaarden van rationaliteit die artsen gebruiken wanneer zij oordelen over de beslissing van patiënten om af te zien van een behandeling.

De resultaten laten zien dat artsen voornamelijk een medisch perspectief benadrukken wanneer zij de beslissing van patiënten om af te zien van een behandeling beoordelen. Voor een arts is het belangrijk of de behandelingsbeslissing een curatieve of een niet-curatieve oncologische behandeling betreft. Patiënten baseren hun beslissing om af te zien van een oncologische behandeling voornamelijk op persoonlijke waarden en ervaringen. Vanuit een medisch perspectief worden beslissingen van patiënten die gebaseerd zijn op persoonlijke waarden en ervaringen over het algemeen als irrationeel beoordeeld en moeilijk te accepteren, met name wanneer het een curatieve behandeling betreft. Artsen hebben een andere houding ten aanzien van niet-curatieve behandelingen. Zij hebben dan minder moeite om de beslissing van patiënten te accepteren.

Artsen gebruiken met name een doelgeoriënteerde rationaliteit en patiënten met name een waardegeoriënteerde rationaliteit. Wanneer patiënten afzien van een niet-curatieve behandeling zijn artsen geneigd de waardegeoriënteerde rationaliteit meer te benadrukken. Een consensus tussen de waardegeoriënteerde benadering van arts en patiënt kan dan optreden, met als gevolg begrip en acceptatie van de arts voor de beslissing van de patiënt. De acceptatie van de arts is cruciaal voor zijn of haar houding ten opzichte van de patiënt: wanneer een arts de beslissing van de patiënt niet accepteert, zal de arts geneigd zijn de patiënt te overtuigen de aanbevolen behandeling te ondergaan. Hierdoor kunnen patiënten ervaren dat ze niet echt vrij zijn om te beslissen, wat kan leiden tot frustratie en miscommunicatie. Wanneer een arts de beslissing van de patiënt wel accepteert, zal dit bijdragen aan de beleving van de patiënt vrij te zijn om te beslissen, te worden begrepen en gerespecteerd in de beslissing, en zal dit dus bijdragen aan een betere arts-patiënt relatie.

Hoofdstuk 3

Beslissingen van patiënten over het accepteren of afzien van een oncologische behandeling worden beïnvloed door verscheidene factoren. Een factor die meer

aandacht behoeft, is de attitude van de patiënt ten aanzien van het einde van het leven. In hoofdstuk 3 worden de attitudes van patiënten ten aanzien van de dood en ten aanzien van het overlijden beschreven in relatie tot hun behandelbeslissingen.

Zeven attitudes ten aanzien van het einde van het leven werden onderscheiden: vechten tegen de dood, vermijden van de dood, angst voor de dood, angst voor het overlijden, regelingen treffen (begrafenis), controle over de dood en het accepteren van de dood. Het merendeel van de patiënten dat had afgezien van een behandeling, accepteerde de dood. Deze patiënten richtten zich voornamelijk op het einde van het leven. Het merendeel van de patiënten dat de aanbevolen behandeling had geaccepteerd, vocht tegen de dood. Deze patiënten richtten zich op hoe in leven te blijven en hoe invulling te geven aan hun leven. Zij zagen de behandeling als levensverlengend en als uitstel van de dood. Het hebben van een sociaal netwerk bleek belangrijk te zijn bij het accepteren van de behandeling. Het accepteren of afzien van behandeling bleek niet gerelateerd te zijn aan angst voor de dood of aan angst voor het overlijden. Echter, een wens voor euthanasie bleek wel gerelateerd te zijn aan angst voor het overlijden. Zowel patiënten die afzagen van behandeling als patiënten die de aanbevolen behandeling accepteerden, spraken over euthanasie. Patiënten hadden een wens voor euthanasie omdat ze controle wilden houden en niet afhankelijk van artsen wilden zijn.

In hoofdstuk 3 wordt geconcludeerd dat het accepteren of afzien van behandeling correspondeert met verschillende attitudes van patiënten ten aanzien van het einde van het leven. Kennis van deze attitudes in een vroeg stadium van de ziekte kan artsen helpen de beslissing van patiënten betreffende oncologische behandelingen te begrijpen.

Hoofdstuk 4

Hoofdstuk 4 gaat in op het principe van de autonomie van de patiënt. Over het algemeen wordt tegenwoordig aangenomen dat patiënten een autonome positie dienen in te nemen bij behandelingsbeslissingen. Hoofdstuk 4 had tot doel te verhelderen hoe het concept patiënten autonomie gestalte krijgt bij patiënten die

afzien van een aanbevolen oncologische behandeling. De belangrijkste vragen waren: (1) wat wordt er verstaan onder patiënten autonomie, en (2) welke factoren zijn van invloed op patiënten autonomie.

De resultaten laten zien dat patiënten autonomie een veelomvattend concept is met uitwijdingen op opvattingen van patiënten autonomie als 'het nemen van beslissingen' en 'het invullen van je eigen leven'. In tegenstelling tot wat over het algemeen wordt aangenomen, blijken patiënten die afzien van een behandeling bij hun beslissing niet zozeer te steunen op de medische informatie over ziekte of behandelingsmogelijkheden, maar worden ze geïnspireerd door hun eigen ervaringen en die van hun naasten. De medische informatie en de rol van de arts beïnvloeden wel de beleving van de patiënt een keuze te hebben ('keuzevrijheid', afhankelijk van de informatie die aan de patiënt is verstrekt) en de beleving vrij te zijn om te beslissen ('vrijheid' zonder referentie aan keuzen, maar afhankelijk van de inmenging van artsen in het besluitvormingsproces). De resultaten laten zien dat de mate van druk die een arts op de patiënt uitoefent om zich te laten behandelen zoals aanbevolen, afhankelijk is van het onderscheid tussen het curatieve of niet-curatieve doel van de behandeling. Er lijkt een verschuiving op te treden in het respecteren van de autonomie van de patiënt welke afhankelijk is van factoren zoals het doel van de behandeling. Er wordt gesuggereerd dat discussie over deze verschuiving voor arts en patiënt opheldering kan geven over de onderliggende gedachten en principes van het besluitvormingsproces.

Hoofdstuk 5

Hoofdstuk 5 geeft een meer ethisch-filosofische uiteenzetting van het concept patiënten autonomie. Er wordt beschreven hoe de relatie is tussen de resultaten van de empirische studie en het liberale idee van patiënten autonomie, het zorgethisch perspectief op patiënten autonomie en de patient-centered medicine benadering van patiënten autonomie. De aandacht is gericht op (1) autonomie als 'het nemen van beslissingen' en 'het invullen van je eigen leven', (2) het idee van vrijheid dat verbonden is met patiënten autonomie, en (3) het perspectief van arts en patiënt in de medische besluitvorming.

In de context van patiënten die afzien van behandeling, kan de autonomie van de patiënt worden beschouwd als de mogelijkheid om te beslissen en de mogelijkheid het eigen leven gestalte te geven. Het respecteren van de autonomie van de patiënt betekent daarom het waarborgen van een keuzemogelijkheid voor de patiënt ('keuzevrijheid') en vraagt om respect voor de manier waarop de patiënt zijn of haar eigen individuele levensdoelen nastreeft ('zijnsvrijheid'). Het lijkt problematisch dat arts en patiënt verschillen in de hoeveelheid aandacht die wordt besteed aan 'keuzevrijheid' en aan 'zijnsvrijheid': artsen benadrukken met name de 'keuzevrijheid' van patiënten en patiënten willen gerespecteerd worden in hun 'keuzevrijheid' en in hun 'zijnsvrijheid'. De liberale traditie wordt bekritiseerd op het niet rekening houden met het perspectief van de patiënt. De liberale traditie zou zich alleen maar richten op het waarborgen van een keuzemogelijkheid voor de patiënt. Echter, in de liberale traditie komt ook het respecteren van het perspectief van de patiënt naar voren, maar dit wordt inderdaad niet erg benadrukt. Verder wordt de liberale traditie bekritiseerd op een te individualistisch idee van patiënten autonomie. In plaats daarvan beschouwen het zorgethisch perspectief en de patient-centered medicine benadering een meer relationele basis van patiënten autonomie. Er wordt aangetoond dat deze relationaliteit aanwezig is bij zowel het waarborgen van een keuzemogelijkheid voor de patiënt als bij het respecteren van de manier waarop de patiënt zijn of haar eigen levensdoelen nastreeft.

In hoofdstuk 5 wordt geconcludeerd dat betreffende het afzien van behandeling, het liberale idee van patiënten autonomie en het zorgethisch perspectief niet zover uiteenlopen als door sommige critici wordt gesuggereerd. Er bestaat hooguit een verschil in welke aspecten er worden benadrukt. Het combineren van de twee perspectieven kan richtinggevend zijn voor een arts-patiënt relatie waarin er aandacht is voor de keuze tussen behandelingsalternatieven en voor het patiënten en het medische perspectief.

Discussie

In de discussie wordt ingegaan op enkele methodologische overwegingen. Deze hebben betrekking op het open exploratieve karakter van de studie en op enkele tekortkomingen van de studie. Het open exploratieve karakter van de studie heeft

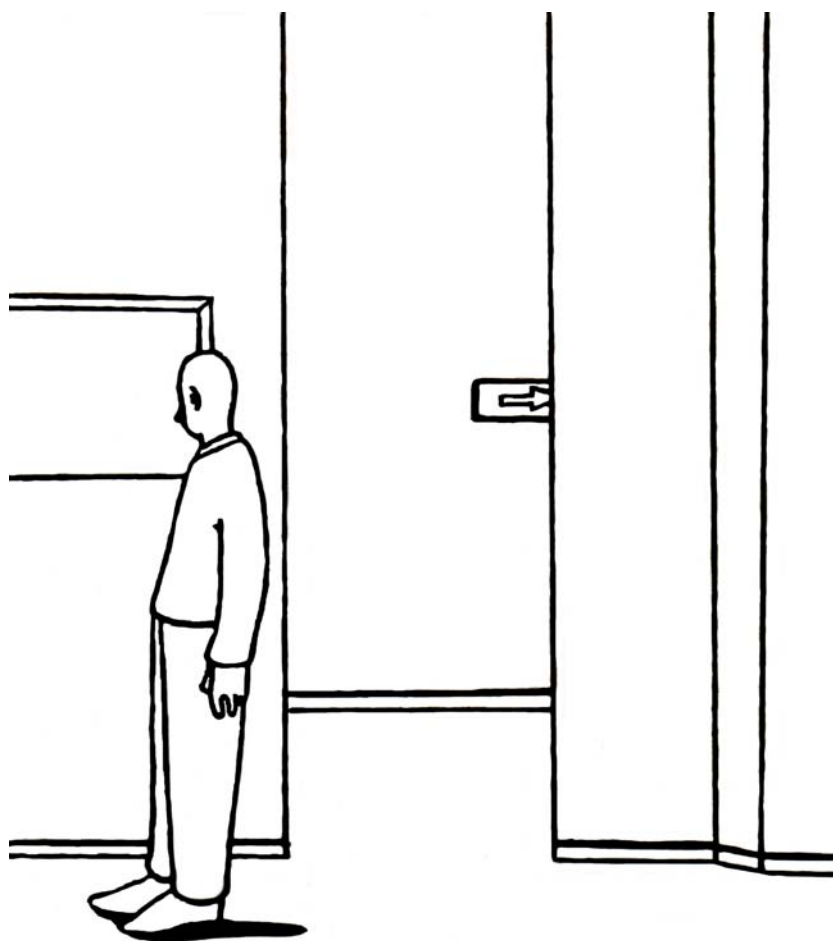
als voordeel dat overwegingen, attitudes en hieraan gerelateerde factoren konden worden gesignaleerd zonder dat deze vooraf bedacht waren. Een ander voordeel is dat gedurende het interviewen, respondenten (artsen en patiënten) gestimuleerd werden om allerlei aspecten van het besluitvormingsproces te noemen zonder dat zij beperkt werden door bijvoorbeeld een lijst met overwegingen die mogelijkwerijs te maken hadden met het besluitvormingsproces. De studie kende ook enkele tekortkomingen. Er wordt ingegaan op: (1) de selectieve groep van respondenten, (2) het aantal respondenten, (3) het geven van wenselijke antwoorden of het willen rechtvaardigen van beslissingen, en (4) de afwezigheid van een één op één match tussen patiënt en arts.

Vervolgens worden de resultaten van de studie in perspectief geplaatst en wordt ingegaan op de onderzoeksvraag: hoe krijgt het concept patiënten autonomie gestalte in het besluitvormingsproces betreffende een oncologische behandeling, met name wanneer patiënten afzien van behandeling. Er wordt aandacht besteed aan de arts-patiënt relatie als beginpunt van behandelingsbeslissingen in de klinische oncologie. In het besluitvormingsproces over oncologische behandelingen krijgt patiënten autonomie gestalte door de manier waarop patiënten beslissingen nemen en hun eigen leven invullen. In deze context is patiënten autonomie gerelateerd aan de manier waarop de arts de patiënt informeert ('keuzevrijheid') en gerelateerd aan de manier waarop de arts rekening houdt met het perspectief van de patiënt ('zijnsvrijheid'). Moeilijkheden en uitdagingen met betrekking tot het geven van informatie aan patiënten en met betrekking tot het rekening houden met het perspectief van de patiënt worden uiteengezet en suggesties voor vervolgonderzoek en voor de medisch opleiding worden gegeven.

Er wordt geconcludeerd dat het geven van informatie en het rekening houden met het perspectief van de patiënt duidelijk een aantal uitdagingen voor de arts met zich meebrengen. De arts dient rekening te houden met alle ethische aspecten van de unieke context waarin de interactie tussen arts en patiënt plaatsvindt: het doel van de geneeskunde en van de behandeling, de voor- en nadelen van de behandeling, en last but not least, het perspectief van de patiënt. Een verstandige reactie op de beslissing van patiënten om af te zien van een aanbevolen behandeling dient rekening te houden met de bijzonderheid van de

situatie. Dit zorgt ervoor dat het nemen van behandelingsbeslissingen een uniek proces van afwegen is in plaats van een 'slam-dunk'.

Dankwoord



Dankwoord

Het onderzoek beschreven in dit proefschrift had ik niet kunnen uitvoeren zonder de medewerking en steun van een aantal mensen. Aan hen wil ik graag deze laatste regels besteden.

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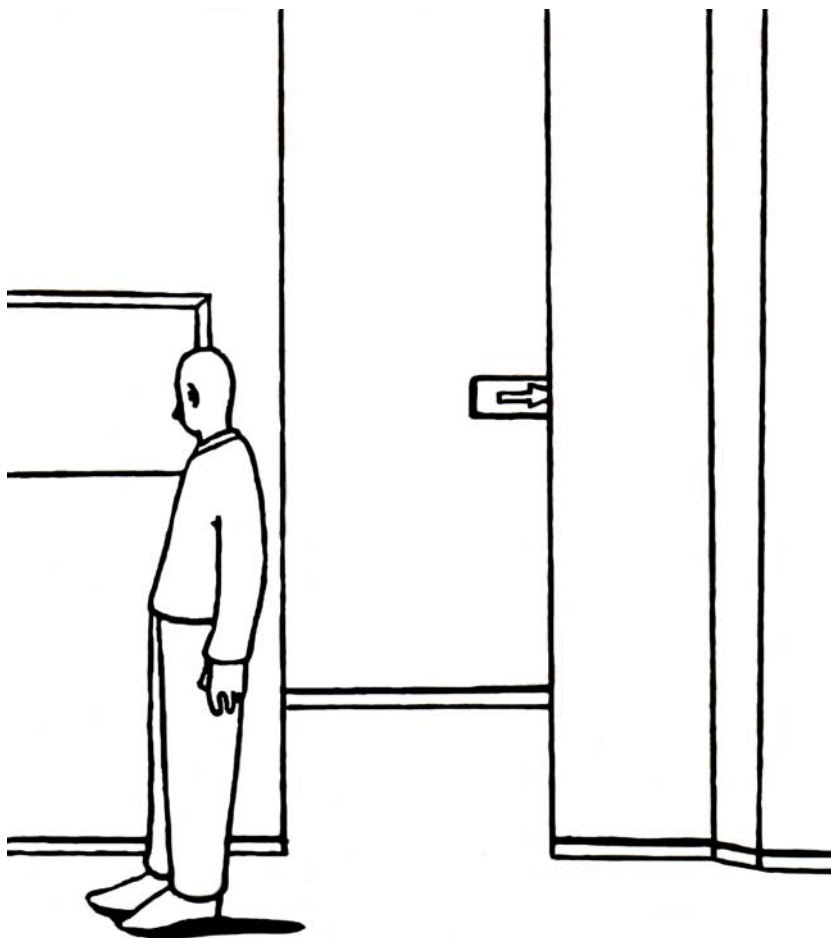
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Titia

Amsterdam, november 2004

Curriculum Vitae

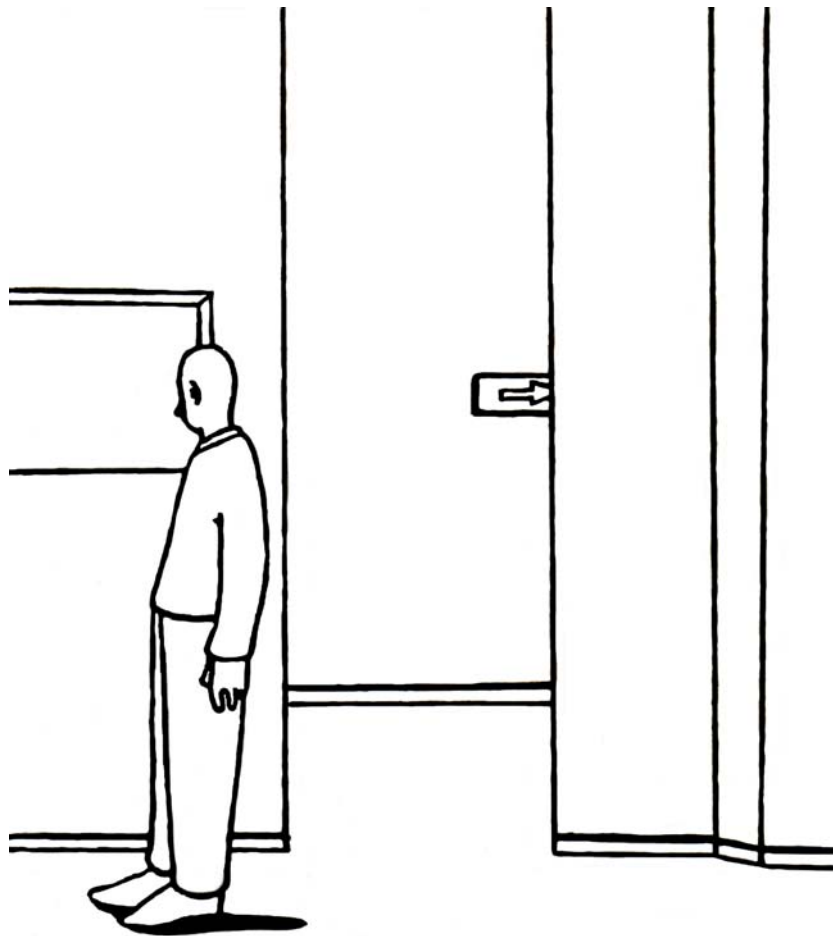


Curriculum Vitae

Titia van Kleffens werd op 28 mei 1976 geboren te Westmaas. In 1994 behaalde zij het VWO diploma aan het Revis Lyceum te Doorn. In datzelfde jaar is zij Biologie gaan studeren aan de Universiteit Utrecht. Na twee onderzoeksstages in de richting Endocrinologie (Faculteit Biologie, Universiteit Utrecht) en Immunologie (Nederlands Kanker Instituut, Amsterdam) en het schrijven van haar afstudeerscriptie (Wilhelmina Kinderziekenhuis, Universitair Medisch Centrum Utrecht), heeft zij nog een specialisatie gedaan in de richting Zorgmanagement, waarbij mensgebonden onderzoek in de gezondheidszorg centraal stond (Juliuscentrum, Universitair Medisch Centrum Utrecht). In 1999 haalde zij haar doctoraalexamen. Van december 1999 tot april 2004 werkte ze bij het Centrum voor Ethiek en Levensbeschouwing, afdeling Filosofie en Medische Ethiek, van het VU medisch centrum te Amsterdam. Daar werd het onderzoek verricht waarvan de resultaten in dit proefschrift beschreven zijn. Vanaf mei 2004 is zij werkzaam als docent Medische Ethiek aan het Ethiek Instituut van de Universiteit Utrecht.

Titia van Kleffens was born on the 28th of May 1976 in Westmaas, the Netherlands. After completing secondary school (1994) she studied Biology at the Utrecht University where she took her MSc. degree in 1999. From December 1999 until April 2004, she worked as a junior researcher at the Center of Ethics and Philosophy, department of Philosophy and Medical Ethics, VU University Medical Center, Amsterdam. The study described in this thesis was performed there. Since May 2004, she has been working as a teacher in Medical Ethics at the Ethics Institute, Utrecht University.

List of publications



List of publications

1. Van Kleffens T, Van Baarsen B, Van Leeuwen E. Patient autonomy in the context of cancer treatment refusal. *Submitted*.
2. Van Kleffens T, Van Baarsen B, Van Leeuwen E. End-of-life attitudes of patients who decide on oncological treatments. *Submitted*.
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